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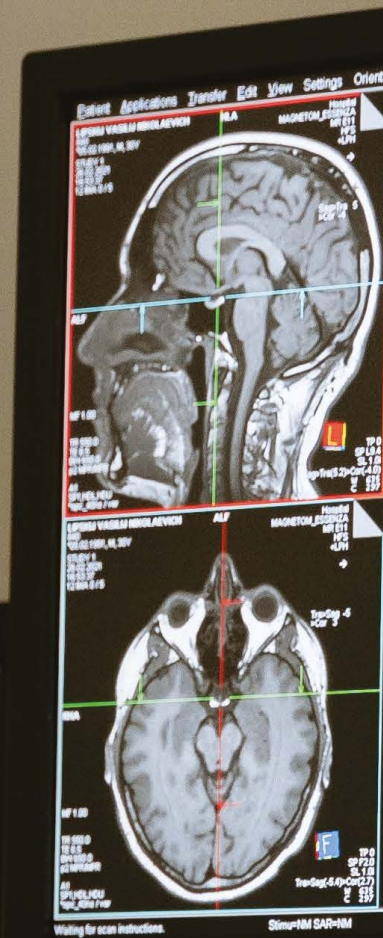
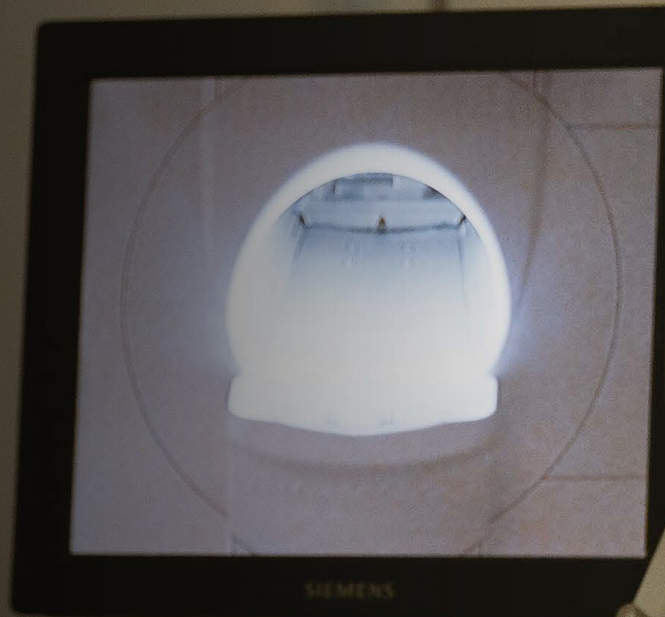
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EVALUATION OF AN ALCOHOL RELATED BRAIN INJURY RESIDENTIAL REHABILITATION UNIT IN NORTHERN IRELAND

A Report by Dr Anne Campbell, Dr Sharon Millen, Diane Watson, Dr Jana Ross and Dr Roger McCorry





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Diane Watson, Dr Jana Ross & Dr Roger McCorry

School of Social Sciences, Education & Social Work, Queen's University,
Belfast^{1,2}

Belfast Health & Social Care Trust⁵
Leonard Cheshire ARBI facility³

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EXECUTIVE SUMMARY

Background: Initiatives are required to identify and provide rehabilitation for individuals with Alcohol Related Brain Injury (ARBI). However, there is very little evidence as regards the outcomes and lived experiences of the patients who often have a myriad of corollary problems including alcohol dependency, homelessness, family dysfunction, poor health, and contact with the criminal justice system. Leonard Cheshire has developed a specialist residential rehabilitation facility for people in Northern Ireland with Alcohol Related Brain Injury. This service is the first of its kind on the island of Ireland and is one element in the network of services required to support people with ARBI.

Objectives and main outcomes: This mixed methods study explored the effectiveness of an ARBI rehabilitation treatment modality available for patients in Northern Ireland on an inpatient basis. In particular, the study sought to ascertain whether the ARBI treatment service improved outcomes for patients (psychological, functional, social and relational) and to determine what is required to sustain and/or improve implementation of the service. The quantitative element focused on measuring the impact of the intervention on psychological well-being, functional ability, familial and social relationships/ community participation/ cognitive ability and maintaining abstinence.

Design: A mixed method design was employed, with individuals with ARBI who were recruited through Leonard Cheshire ARBI service using purposive sampling over a 16-month period. A range of psychometric measures were used to assess psychological well-being, functional ability, familial and social relationships/community participation/ cognitive ability and maintaining abstinence at base line and at five junctures throughout the project time frame. Qualitative data was collected over 4 timepoints: baseline (n=20), 6 months (n=15), 12 months (n=6) and at discharge (n=8). Remote interviews were conducted with family members (n=10) in order to capture their lived experience and views. Staff interviews (n=6) captured views on the implementation of the model as well as their perceptions of strengths, weakness and benefits of the service and external influences that might impact on its implementation and effectiveness.

Findings: Quantitative findings for service users showed significant positive differences across T1 and other junctures for physical and cognitive functioning, anxiety, occupational performance and satisfaction, quality of life and societal participation, there were no significant differences between all time points at baseline and at the three-month juncture for psychological well-being and depression. Qualitative findings for residents across 4 timepoints from baseline to time of discharge indicated an overall improvement in all outcomes. Staff from within the unit felt that the ARBI multidisciplinary holistic approach had a positive impact on residents' outcomes and was also cost effective in that these individuals were no longer frequenting A&E departments and the judicial system and instead were now able to live stable lives without relentless chaos whilst residing in the unit.

Conclusions: Overall, the ARBI holistic intervention significantly improved psychological wellbeing, social relationships/community participation, functioning abilities and abstinence from alcohol, particularly when residents were residing in the unit. Whilst the residential unit provided structure and a protective environment, residents required ongoing support post discharge for their addictive behaviours. An outreach intervention for these individuals is currently being piloted.

Keywords: Alcohol Related Brain Injury, Rehabilitation, Abstinence, Harm Reduction.

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SECTION 1: INTRODUCTION

Alcohol-Related Brain Injury (ARBI) is an umbrella term used to describe the damage to the brain because of long-term heavy drinking. The symptoms of Alcohol Related Brain Injury vary but include problems with cognitive functioning such as memory loss, difficulty with familiar tasks and with processing new information, depression and irritability, erratic behaviour, concentration problems and poor decision-making (Mental Welfare Commission, 2019). Alongside cognitive problems, individuals with ARBI may experience physical illnesses which include liver damage, heart problems, high blood pressure and malnutrition. Symptoms can range from mild to severe and many of these symptoms can improve if the person is diagnosed in time and appropriate treatment provided. In fact, around 75% of individuals with ARBI who receive the appropriate treatment do make some recovery with 25% making a complete recovery (Alcohol Change UK 2020). However, since ARBI comprises a variety of conditions caused by heavy drinking, different treatment approaches have been found to help different people. It is therefore crucial that patients are assessed individually by a multidisciplinary team of professionals and a tailored approach is provided to meet the person's specific needs.

The evidence base for rehabilitating ARBI is still in its infancy (Svanberg & Evans, 2013, Schrader et al 2021, Scholin et al 2019). To date, two types of evidence exist with regard to the effect of therapeutic intervention: Training in specific cognitive domains and also generic rehabilitation programmes (Wilson, 2011). Svanberg & Evans (2013) conducted a systematic review of interventions focusing on neurorehabilitation of cognitive impairment relating to ARBI (including Wernicke-Korsakoff syndrome). Sixteen studies were included in the review, most of which addressed rehabilitation of memory impairments associated with Korsakoff's syndrome. Three studies outlined service models or approaches for generating advances in service development for this population. However, the variance in methodologies and overall quality of evidence made any possible conclusions tentative (Svanberg & Evans, 2013). Wilson et al (2012) followed 41 patients (over 25 months) who attended a phased rehabilitation programme in a community setting. Thirty-two patients were either abstinent or categorised as 'controlled drinkers' and were placed in appropriate community settings. Acute hospital admissions were reduced by 85% and various domains of a neuropsychiatric assessment tool showed improvement in scores.

There is some evidence as regards the efficacy of long-term care for Korsakoff's syndrome within a nursing home setting (Oud, 2014) and intensive inpatient neuro rehabilitation (Schrader et al, 2021). The latter was based on a longitudinal case study, which illustrated the benefits of neuro rehabilitation for alcohol related brain injury. Findings demonstrated how skills and strategies learned in the inpatient setting, translate into living well and independently, and how the latter promotes further improvement over long periods post discharge. However, there is very little evidence as regards the lived experiences of the patients who often have a myriad of corollary problems including homelessness, family dysfunction, contact with the criminal justice system and poor health. It is anticipated that these mixed methods investigation by the Leonard Cheshire collaborative ARBI service will have a positive impact on the future shaping of service delivery and success of the provision of services in this area.

1.1 ARBI LEONARD CHESHIRE RESIDENTIAL REHABILITATION SERVICE

Leonard Cheshire has developed a residential rehabilitation facility for people in Northern Ireland with ARBI. It is designed as a post-acute service and is the first of its kind on the island of Ireland. This service is one element in the network of services required to support people with ARBI.

The treatment of ARBI has previously been a particularly under resourced and neglected area within Northern Ireland. As ARBI caseloads significantly increase in acute hospitals across NI, the facility offers a focused and tailored approach to the post-acute treatment of ARBI patients who are referred from various pathways (see appendix 2).

Leonard Cheshire and Belfast Trust were originally tasked with the development of a 14-bed residential rehabilitation facility for people in NI with ARBI for a period up to 2-3 years. The unit opened in January 2020, prior to the initial pandemic lockdown period. The current service is regional, offering placement for people from all five Health and Social Care Trust areas.

The intervention is based upon the existing psychosocial model for rehabilitation of patients with ARBI by Wilson et al. (2012) and consists of five phases: Stabilisation, psychosocial assessment, therapeutic rehabilitation, adaptive rehabilitation and social integration and relapse prevention (see appendix 3). The ARBI model specifically focuses on 4 key areas; (i) social relationships and community participation, (ii) functional abilities, physical, cognitive, activities of daily living and self-care, (iii) psychological wellbeing and (iv) maintaining abstinence relapse prevention (see appendix 4).

1.2 MODEL OF SUPPORT

The model of support adopted is based on the following evidence-based approaches:

(i) Recovery and Reablement models: supporting the persons potential for recovery, supporting them to set new goals, take part in relationships and activities that are meaningful and build a positive sense of self;

(ii) Person Centred Planning: ensuring that the individual is at the centre of decision making in relation to their lives, treating them with dignity and respect and supporting their beliefs, values and preferences;

(iii) Strengths Based Approach: focusing on the person and families' strengths, interests, and support systems to aid recovery and empowerment;

(iv) Positive Behaviour Support: using management strategies designed to help staff understand why challenging behaviour occurs, address the motivation behind the behaviour and alter the learning environment to provide positive support and encouragement for the desired behaviour.

1.3 STAFFING

Core service staff

At present the core service consists of a Service Manager (full time) and Deputy Service Manager whose roles are to provide effective operational management of the unit, with responsibility for the delivery, safety and quality of the care provided. There is also a Clinical Lead (0.6WTE) and a Clinical Assistant (1WTE), a Rehabilitation Lead and Rehabilitation Assistants during the day. Two staff providing waking night cover in order to provide the support required to individuals to enable them to participate in actions and activities designed to promote their rehabilitation. The core team also includes a Service Administrator (0.43 WTE), and a Cook (0.71WTE).

Transitional Service Staff

The current transitional service consists of an Occupational Therapist who completes two half day sessions per week; and a Clinical Neuropsychologist, a Speech and Language Therapist and a Physiotherapist who complete 2 half-day sessions per month within the unit. The transitional team's role is to input into preliminary screening, assessment, and rehabilitation planning as well as to provide ongoing support to core service staff and to service users.



SECTION 2: METHODOLOGY

This section sets out the main research questions and objectives for the study and outlines the study design and methodology.



2.1 RESEARCH QUESTIONS AND OBJECTIVES

The study sought to address five research questions:

1. Does the ARBI treatment residential service improve psychological, functional, social, and relational outcomes for patients?
2. What is the lived experience of patients receiving the holistic rehabilitation programme?
3. What is the experience of family members of those receiving the treatment?
4. What is the experience of staff regarding the approach and perceived impact on patients?
5. What is needed to sustain and/or improve implementation?

In doing this, the study had the following core objectives:

1. To ascertain whether the ARBI treatment service improves psychological, functional, social, and relational outcomes for patients.
2. To explore the lived experience of patients who reside in the unit.
3. To capture the views and experiences of family members/carers of those residing in the ARBI facility and to obtain the views and experience of staff from within the unit, regarding the approach and perceived impact on patients.
4. To ascertain what is required to sustain and/or improve implementation.

2.2 STUDY DESIGN

Reflecting the main research questions and objectives for the study this mixed methods study employed both a quantitative and qualitative approach to explore whether the holistic model employed within the ARBI facility improved the psychological, functional, and relational outcomes for patients. Qualitative data was captured regarding the lived experience and views of the patients and family members/carers who participated in the Leonard Cheshire ARBI treatment modality, alongside staff views.

2.3 QUANTITATIVE DATA COLLECTION

The quantitative phase used a repeated design method to gather data for comparison at different time points. Outcome data were collected from patients within the study on 5 occasions (baseline, 3, 6, 12 and 18 months) using standardised measures designed to assess the impact of the programme on each study outcome during the resident’s stay in the unit. The quantitative data was collected by a qualified clinician from within the unit.

Primary outcomes included positive psychological wellbeing, functional abilities, social relationships and community participation. Quantitative data collection took place over an 18-month period (i.e., from February 2021- August 2022).

Table 1. Number of service users in qualitative phase

Timepoint	Number of participants
T1 baseline	23
T2 3 months	16
T3 6 months	17
T4 12 months	11
T5 18 months	7

2.4 OUTCOME MEASURES

Social Relationships and Community Participation was assessed using the 8-item Mayo-Portland Participation Index (M2PI) from MPAI-4. The Mayo-Portland Adaptability Inventory – (MPAI) (Malec, 2005), was primarily designed to assist in the clinical evaluation of people during the post-acute period following acquired brain injury (ABI), and to assist in the evaluation of rehabilitation programs designed to serve these people. The current 4th Edition (MPAI-4) consists of 30 items and is divided into 3 subscales (Ability, Adjustment and Participation index) which contribute to the overall score. It also includes a subsection on pre-existing and associated conditions, but this section is only used to identify special needs and circumstances with the scores not contributing to the overall score. The most recent psychometric analysis of the MPAI-4 demonstrated satisfactory internal consistency (Cronbach's alpha=.89) for the entire measure and for each of the three subscales meaning that the MPAI-4 reliably and consistently measures the individual constructs in each of the subscales as well providing a consistent and reliable overall adaptability score.

Functional Abilities was assessed using Mayo-Portland Ability 12-item subscale of MPAI-4. The Canadian Occupational Performance Measure - COPM (Law et al., 1990) was also used to assess functional abilities. COPM is an individualised outcome measure commonly used in occupational therapy. It helps individuals identify and prioritise issues that restrict their everyday living and occupational performance. It yields two scores: one for performance and one for satisfaction. Higher scores indicate better performance or greater satisfaction.

Cognitive Abilities was assessed using the Addenbrookes Cognitive Assessment (ACE-III). ACE-III (Hodges, 2017) is a brief measure of five cognitive domains, specifically attention, memory, verbal fluency, language, and visuospatial abilities. The maximum score is 100 and higher scores are indicative of better cognitive functioning. RBANS (Randolph, 1998) is commonly used to assess cognitive functioning. It consists of 12 subtests that yield five index scores and a total score. The five indices include immediate memory, visuospatial/constructional, language, attention, and delayed memory. Higher scores indicate better functioning.

Positive Psychological Wellbeing was assessed using the (9-item) Mayo-Portland – Adjustment subscale of MPAI-4. It was also assessed via the Health of the Nation Outcomes Scale for Acquired Brain Injury (HoNOS-ABI) (Fleminger,1999) assesses functions and outcomes in four domains; 1) behavioural, which includes aggression and overactivity, self-harm and substance abuse, 2) impairment in cognition and physical health, 3) symptoms, which include problems with hallucinations and delusions, depression and others, and 4) social, which includes social relations, general functioning, housing and other activities. There are 12 items in total and higher scores are indicative of more severe problems. It is a widely used routine clinical outcome measure, particularly in English mental health services (Glover & Sinclair, 2000). Cronbach's alpha has ranged in studies from 0.59 to 0.76 suggesting moderately high internal consistency and low item redundancy. Overall, the HoNOS seems to have adequate or good validity, reliability, sensitivity to change and acceptability.

The Quality of Life after Brain Injury overall score - QOLIBRI (Von Steinbüchel et al, 2010) is a measure of health-related quality of life, specifically developed for individuals who have suffered a traumatic brain injury. Scores on the overall scale can range from 0-100 and higher scores indicate better quality of life.

The Hospital Anxiety and Depression Scale - HADS (Snaith & Zigmond, 1983) is a 14-item self-report measure of depression (HADS-D) and anxiety (HADS-A). Each of the two subscales comprises seven items and patients are asked to rate the items in relation to their mood over the past week. HADS-D assesses anhedonia and feelings of slowing down. HADS-A assesses autonomic anxiety and tension and restlessness. Higher scores on each subscale indicate greater distress.

Data from MPAI-4, QOLIBRI, COPM, RBANS, HADS and ACE III were collected at baseline, 6, 12 and 18 months during the residents stay in the unit. Only data for HADS was collected at 3 months as the remaining measures could only be administered every 6 months.

TABLE: DETAILS AND TIMING OF DATA COLLECTION

Table 2. Details and timing of data collection

OUTCOME	MEASURES	AV. MINS TO COMPLETE	BASE LINE	3 MTHS	6 MTHS	12 MTHS	18 MTHS
Social relationships/ Community participation	Mayo-Portland – Participation scale	5		X	X	X	X
Functional abilities	Mayo-Portland – Functional scale	5		X	X	X	X
	Canadian Occupational performance Measure (COPM)	10	X		X	X	X
Cognitive abilities	Addenbrooke’s Cognitive Assessment (ACE-III)	10	X		X	X	X
	Repeatable Battery for the Assessment of Neuropsychological Status - Brief (RBANS)	10	X	X	X	X	X
Psychological wellbeing	Mayo-Portland-	5		X	X	X	X
	Health of the Nation Outcome Scales (HoNOS)	5	X	X	X	X	X
	Hospital Anxiety & Depression Scale (HADS)	5	X	X	X	X	X
	Quality of Life after Brain Injury (QOLIBRI overall score)	5	X		X	X	X
Maintaining abstinence	Mayo-Portland-Pre-existing & associated conditions scale	5		X	X	X	X



2.5 QUALITATIVE DATA COLLECTION

2.5.1 Service user interviews

Data was gathered via interviews for service users over 4 timepoints: 20 service users at baseline, 15 at 6 months, and 6 at the 12-month juncture. In addition, there were 8 residents discharged during the 16-month timeframe of qualitative data collection (April 2021 – August 2022) and 8 discharge interviews were conducted prior to the resident leaving the unit.

Table 3. Number of service users in qualitative phase

Timepoint	Number of service users
T1 baseline	20
T2 6 months	15
T3 12 months	6
Discharge	8
TOTAL	49

2.5.2 Interviews with family members/ carers

Remote interviews were conducted with 10 family members via Zoom online conferencing software. There were 4 males and 6 females who participated in the online interviews. Data was collected throughout the study timeframe in order to ascertain the lived experience of family members who have helped to support and care for their relatives prior to admission and during and the in-patient programme.

2.5.3 Interviews with workers

Face to face interviews were conducted with 6 members of staff from Leonard Cheshire Alcohol Related Brain Injury Unit. The staff interviews captured views on the implementation of the model as well as their perceptions of strengths, weakness and benefits of the service and external influences that might impact on its implementation and effectiveness.

Each interview lasted between 20-30 minutes. All interviews were designed around a topic guide to ensure consistency of coverage but allowed scope for the individual circumstances (semi-structured). Interviews were conducted after obtaining written consent. All interviews were audio recorded with consent, transcribed verbatim, and anonymised.

2.6 ELIGIBILITY

Participants were eligible for the study if they had been successfully referred to the Leonard Cheshire ARBI residential rehabilitation facility and had capacity to consent.

Staff were eligible to take part if they were currently employed by Leonard Cheshire and worked in the unit.

Relatives/ carers were eligible to participate if they were related to or had caring responsibilities for a resident within the Leonard Cheshire facility.

Individuals were excluded if they did not meet any of the inclusion criteria. If a translator was available those who did not speak English could participate.

2.7 RECRUITMENT AND INFORMED CONSENT

All recipients of the service between February 2021 and August 2022 were invited to take part. All eligible participants were informed about the study by the clinical lead within the unit and were provided with accessible, written information and asked if they would consider participating. They were encouraged to read the Participant Information Sheet and there was time to ask the researcher any questions before they made their decision as to take part in the study. One eligible participant declined to participate.

This study did not recruit anyone without the capacity to consent. Patient capacity was certified by a suitably qualified clinician before data collection. The researcher also explained that the data obtained during the study would be kept secure and confidential, and that all data would be anonymised i.e., that no one would be identifiable from the output of the study.

The relatives of those patients who agreed to take part were contacted by the service manager, provided with written information about the study and were asked to send a consent form and return in a stamped addressed envelope to the researcher, providing their contact details to enable future contact from the researcher.

In terms of recruiting staff, the service manager forwarded an email (from the research team) to the workers from within the unit in the first instance, outlining the details of the study and requesting permission to be contacted by a researcher. If permission was provided, the researcher then met with the member of staff, answered any questions, and gained written consent prior to the commencement of the face-to-face interview.

2.8 PARTICIPANTS

The study sought to recruit 20 service users who had an ARBI diagnosis, 20 relatives/carers and 6 workers. Final participant numbers showed that 23 service users were recruited to participate in the quantitative phase of the research, whilst 20 took part in qualitative phase at baseline. Ten family members participated in remote interviews via Zoom, whilst 6 workers from within the Leonard Cheshire unit took part in face-to-face interviews.

2.9 SAMPLING STRATEGY

A purposive sampling technique was used to identify participants who were successfully referred to the new ARBI facility. Service users were invited to take part in the research during the 16 months of data collection and were interviewed at baseline, 6 and 12-month time points and/or at discharge (if discharged prior to these timepoints). Family members/carers of those residing in the ARBI unit were also invited to take part in an interview to capture their views and experiences regarding the service.

Purposive sampling was also employed to select workers to ensure a range of informants from a range of positions, length of service and gender. In total 6 workers were interviewed (see staff interview section for details).

2.10 ETHICS

Ethical approval for the study was secured from the HSC Office for Research Ethics Committees Northern Ireland (ORECNI) A on 30th September 2020, (REC reference number: 20/NI/0108). There was a 4-month delay in the commencement of quantitative data collection and a 6-month delay in qualitative data collection due to Covid-19 pandemic and restrictions within the residential care facilities.

2.11 ANALYSES

Statistical analysis was carried out at the individual level. Every effort was made to obtain outcome measures for participants. Data from the psychometric tools used was input into a separate SPSS database (see service user quantitative analysis on pg. 24 for further detail).

Data from the qualitative semi structured interviews with service users, family members/carers and workers were analysed using the principles of thematic content analysis (Burnard, 1991). Data analysis ran concurrently with data collection to ensure the process was as iterative as possible. An essentialist/realist approach was employed, which attempted to theorise motivation, experience and meaning in a straightforward manner.

A simple largely unidirectional relationship was assumed between meaning, experience and language (Braun & Clarke, 2006). NVivo12 was used to assist with the organisation of data. Inter-rater checks on the semi structured interview data were carried out by two members of the research team and emerging themes and ideas were discussed and reflected upon by the team.



SECTION 3: SERVICE USER AND FAMILY/ CARER FINDINGS

The following two sections present the study findings. This chapter outlines the demographic characteristics of the service user sample, the service user quantitative results and the qualitative findings from the service user and family/carer interviews.



3.1 DEMOGRAPHIC CHARACTERISTICS OF SERVICE USERS

Table 4. Demographic Characteristics of service users

Demographic Characteristics	Total sample
GENDER	
Men	17
Women	6
AGE (YEARS)	
Women	
Range	40-64
Mean	50
Men	
Range	42-74
Mean	54
DURATION OF STAY (MONTHS)	
Range	3 – 30
Mean	14.3

Almost two thirds of service users who participated in this study were male (17/23) with an age range of 42-74 years. Around a third were female (n=6) with ages ranging from 40-64 years. At the final point of data collection, residents had stayed within the unit from a period of 3 months to 30 months, with a mean stay of 14 months.

Service users presented with a range of educational backgrounds and employment history, from unemployed to professions including, business owner, solicitor, and university staff. Reasons for escalated drinking patterns reported by service users included, major surgery causing disfigurement, sudden family bereavement, domestic violence, PTSD, childhood trauma, relationship breakdowns and excessive social drinking.

3.2 QUANTITATIVE FINDINGS FROM SERVICE USER ASSESSMENTS

In order to examine the patients’ neuropsychological functioning over time, for each respective measure, data from T1 (baseline) were compared with data from the other time points. It is important to note that data were not available for all measures at all time points. Additionally, the statistical difference tests were not carried out if the sample size was less than five. Table x outlines the tests that were conducted. Paired samples

t-tests were used to compare the time points when the data were normally distributed. For data that were not normally distributed, Wilcoxon signed rank tests were used. All reported p-values are one-tailed. Cohen’s d effect sizes are reported for t-tests and correlations are reported for Wilcoxon tests. T1 is data collected at baseline, T2, at 3 months, T3 at 6 months, T4 at 12 months and T5 at the 18-month timepoint.

Table 5. Tests of differences carried out across time points.

Measure	T1 vs. T2	T1 vs T3	T1 vs T4	T1 vs T5
MP ability	X	Yes	Yes	Yes
MP adjustment	X	Yes	Yes	Yes
MP participation	X	Yes	Yes	Yes
MP conditions	X	Yes	Yes	Yes
MP total	X	Yes	Yes	Yes
HADS depression	Yes	Yes	Yes	Yes
HADS anxiety	Yes	Yes	Yes	Yes
HONOS	X	Yes	Yes	Yes
QOLIBRI overall	X	Yes	Yes	Yes
ACE III	Yes	Yes	Yes	X
COPM performance	X	Yes	Yes	X
COPM satisfaction	X	Yes	Yes	X
RBANS	X	Yes	Yes	X

Mayo-Portland Adaptability Inventory (MPAI-4)

The Ability Index scores did not change significantly between T1 and T3, but there was a significant decrease in the scores between T1 and T4 (large effect size), and also between T1 and T5 (medium to

large effect size), suggesting an overall improvement in the areas contributing to the Ability Index.

There was also an improvement on the Participation Index, with scores decreasing significantly from T1 to T3 (medium effect size), from T1 to T4 (large effect size) and from T1 to T5 (large effect size).

The Adjustment Index scores and scores on the pre-existing and coexisting conditions did not change significantly over time.

For the overall MPAI-4 scores, there was no significant change between T1 and T3 and between T1 and T4, but there was a significant decrease in the scores from T1 to T5 (large effect size), suggesting an overall improvement.

Table 6 provides descriptive statistics, significance tests and effect sizes for all comparisons.

Table 6. Mayo-Portland Adaptability Inventory (MPAI-4) descriptive statistics, significance tests and effect sizes

Time points	N	M (SD)	Median (IQR)	Test of difference	Effect size
Ability Index					
T1 vs T3	17	46.82 (8.38) vs. 45.41 (14.31)	-	t = 0.56, df = 16, p = .291	d = 0.14
T1 vs T4	11	45.09 (6.93) vs. 38.18 (8.68)	-	t = 2.97, df = 10, p = .007	d = 0.90
T1 vs T5	7	-	47.00 (14) vs. 35.00 (17)	Z = -1.87, p = .031	r = -0.71
Adjustment Index					
T1 vs T3	17	51.00 (10.97) vs. 54.06 (10.61)	-	t = -0.84, df = 16, p = .208	d = -0.20
T1 vs T4	11	52.73 (11.82) vs. 50.09 (7.31)	-	t = 0.75, df = 10, p = .236	d = 0.23
T1 vs T5	7	54.86 (11.65) vs. 52.14 (7.47)	-	t = 0.55, df = 6, p = .301	d = 0.21
Participation Index					
T1 vs T3	17	66.06 (11.49) vs. 60.82 (12.23)	-	t = 1.79, df = 16, p = .046	d = 0.43
T1 vs T4	11	65.55 (10.36) vs. 54.91 (7.91)	-	t = 3.51, df = 10, p = .003	d = 1.06
T1 vs T5	7	71.29 (5.31) vs. 58.00 (14.25)	-	t = 3.10, df = 6, p = .011	d = 1.17
Pre-existing or coexisting conditions					
T1 vs T3	17	6.82 (3.52) vs. 6.06 (3.80)	-	t = 0.60, df = 16, p = .280	d = 0.14
T1 vs T4	11	7.55 (4.08) vs. 7.09 (3.53)	-	t = 0.33, df = 10, p = .375	d = 0.10
T1 vs T5	7	-	5.00 (5) vs. 4.00 (3)	Z = -1.29, p = .099	r = -0.49
MPAI total score					
T1 vs T3	17	49.76 (10.83) vs. 52.24 (12.27)	-	t = -0.71, df = 16, p = .245	d = -0.17
T1 vs T4	11	49.00 (12.17) vs. 45.36 (7.30)	-	t = 0.95, df = 10, p = .181	d = 0.29
T1 vs T5	7	55.14 (6.91) vs. 47.29 (11.37)	-	t = 1.96, df = 6, p = .049	d = 0.74

HADS

There were no significant differences in HADS-D scores over time. There was a significant decrease in the HADS anxiety scores between T1 and T2 (large effect size), suggesting an improvement in anxiety symptoms. The scores did not change significantly between T1 at T2, T3 or T4.

Table 7. HADS descriptive statistics, significance tests and effect sizes

Time points	N	M (SD)	Test of difference	Effect size
Depression				
T1 vs T2	16	5.44 (5.02) vs. 5.50 (4.83)	t = -0.09, df = 15, p = .466	d = -0.02
T1 vs T3	14	4.86 (4.42) vs. 5.21 (5.41)	t = -0.028, df = 13, p = .391	d = -0.07
T1 vs T4	11	6.18 (5.38) vs. 4.09 (4.23)	t = 1.57, df = 10, p = .074	d = 0.47
T1 vs T5	5	7.00 (4.36) vs. 5.40 (3.29)	t = 1.73, df = 4, p = .080	d = 0.77
Anxiety				
T1 vs T2	16	9.31 (3.81) vs. 7.00 (4.31)	t = 3.25, df = 15, p = .003	d = 0.81
T1 vs T3	14	7.64 (4.29) vs. 6.07 (5.70)	t = 1.41, df = 13, p = .092	d = 0.38
T1 vs T4	11	8.00 (3.79) vs. 6.64 (4.11)	t = 1.24, df = 10, p = .121	d = 0.37
T1 vs T5	5	9.20 (2.59) vs. 8.00 (4.06)	t = 1.12, df = 4, p = .162	d = 0.50

HoNOS-ABI

There were significant differences in HoNOS-ABI scores across time, with significantly lower scores between T1 and T3 (large effect size), T1 & T4 (large effect size) and T1 and T5 (large effect size), suggesting improvements in overall functioning.

Table 8. HoNOS-ABI descriptive statistics, significance tests and effect sizes

Time points	N	M (SD)	Test of difference	Effect size
T1 vs T3	17	19.82 (8.37) vs. 9.35 (7.31)	t = 4.23, df = 16, p < .001	d = 1.03
T1 vs T4	10	21.10 (5.70) vs. 8.20 (3.36)	t = 9.31, df = 9, p < .001	d = 2.94
T1 vs T5	7	19.14 (5.30) vs. 8.14 (4.06)	t = 7.35, df = 6, p < .001	d = 2.78

QOLIBRI

There were significant differences in QOLIBRI overall scores across time, with the scores being significantly higher at T3 (large effect size), T4 (large effect size) and T5 (large effect size), compared to T1, suggesting an improvement in health-related quality of life over time.

Table 9. QOLIBRI descriptive statistics, significance tests and effect sizes

Time points	N	M (SD)	Test of difference	Effect size
T1 vs T3	10	50.97 (26.72) vs. 19.70 (8.34)	t = 4.07, df = 9, p = .001	d = 1.29
T1 vs T4	10	54.01 (18.10) vs. 23.30 (4.24)	t = 6.46, df = 9, p < .001	d = 2.04
T1 vs T5	6	48.18 (8.66) vs. 20.17 (3.82)	t = 8.07, df = 5, p < .001	d = 3.30

ACE-III

There were significant differences in ACE scores across time, with the scores being significantly higher at T2 (large effect size), T3 (large effect size), and T4 (large effect size), compared to T1, suggesting improvements in cognitive abilities.

Table 10. ACE-III descriptive statistics, significance tests and effect sizes

Time points	N	M (SD)	Test of difference	Effect size
T1 vs T2	7	60.29 (25.32) vs. 72.43 (24.30)	t = -3.00, df = 6, p = .012	d = -1.13
T1 vs T3	10	33.30 (31.35) vs. 76.70 (12.76)	t = -5.62, df = 9, p < .001	d = -1.78
T1 vs T4	10	16.50 (6.43) vs. 72.80 (16.03)	t = -12.17, df = 9, p < .001	d = -3.85

COPM

The COPM performance scores did not change significantly from T1 to T3, but there was a significant increase in the scores from T1 to T4 (large effect size), suggesting an increase in occupational performance.

Similarly, the COPM satisfaction scores did not change significantly from T1 to T3, but there was a significant increase in the scores from T1 to T4 (large effect size), suggesting an increase in occupational satisfaction.

Table 11. COPM descriptive statistics, significance tests and effect sizes

Time points	N	M (SD)	Median (IQR)	Test of difference	Effect size
Performance					
T1 vs T3	15	-	4.60 (3) vs. 4.80 (4)	Z = -0.41, p = .342	r = -0.10
T1 vs T4	6	3.83 (2.09) vs. 6.13 (2.46)	-	t = -2.32, df = 5, p = .034	d = -0.95
Satisfaction					
T1 vs T3	15	-	4.20 (3) vs. 4.20 (5)	Z = -0.41, p = .342	r = -0.10
T1 vs T4	6	2.70 (0.89) vs. 4.82 (2.95)	-	t = -2.48, df = 5, p = .028	d = -1.01

RBANS

The RBANS scores did not change significantly from T1 to T3, but there was a significant increase in the scores from T1 to T4 (large effect size), suggesting an improvement in cognitive functioning.

Table 12. RBANS descriptive statistics, significance tests and effect sizes

Time points	N	M (SD)	Median (IQR)	Test of difference	Effect size
T1 vs T3	8	62.00 (16.28) vs. 64.63 (17.28)	t = -0.74, df = 7, p = .243	d = -0.26	r = -0.10
T1 vs T4	8	61.25 (10.87) vs. 73.38 (15.86)	t = -2.59, df = 7, p = .018	d = -0.92	d = -0.95

3.2.1 SUMMARY OF SERVICE USER QUANTITATIVE FINDINGS

Quantitative findings showed significant positive differences between T1 and subsequent time points for physical and cognitive functioning, anxiety, occupational performance and satisfaction, quality of life and societal participation. There were no significant differences between all time points, at baseline and at the three-month juncture for psychological well-being and depression.



3.3 QUALITATIVE FINDINGS FROM SERVICE USERS AND FAMILY/ CARERS

Face to face interviews were conducted with service users at baseline, 6 month and 12-month timepoints during their stay in the unit and for those who were being discharged, there was an exit interview (n=8). The total sample was n= 49; 20 participants were interviewed at baseline, 15 at 6 months, 6 at the 12-month timepoint and 8 participants at time of discharge.

The qualitative findings were organised and presented into the following categories: socio economic history of service users, cognitive functioning, daily living skills, physical health, psychological wellbeing, social relationships and group participation, desire to remain abstinent, general overview of the service and suggestions on how to the improve service.

Table 13. Number of service users interviewed at each timepoint.

Timepoint	Number of service users
T1 baseline	20
T2 6 months	15
T3 12 months	6
Discharge	8
TOTAL	49

Family members or carers of those who resided in the unit between April 2021 and August 2022 were also invited to take part in a remote interview. Ten relatives consented to participate and their lived experience and views are also included in this section.

3.3.1 SOCIO-ECONOMIC HISTORY OF SERVICE USERS

Education and employment

The demographics and socioeconomic background of the service users varied significantly. Ages ranged from 40-74 years old with a mean age of 52 years. Around three quarters of residents were male. In terms of educational background and employment history, around half had little or no educational qualifications, whilst the other half had a range of qualifications from GCSE to Master's Level. Some had left school at a young age to pursue employment, two had a family business, two had previously worked in professional occupations whilst others had trades.

"I was quite academic, I went to a grammar school, I did a [XXX] degree and an MBA, on the education front I'm doing ok we had a family business and I worked for a [business] in [location] for a few years and then I came back to Belfast. I then went into the family business so to speak and then they sold it on about 2 years ago. I've been a stay-at-home father since, my wife works away a lot"....(LC019).

"I left school when I was 14 and a half. That's why I have no education. The farmer beside me, I used to work with him whenever I was 14 and then in June that year the harvest came up and I never went back to school.... It was common in my time.... I always had a job to go to, you had to go out and do that to get clothes to put on your back and shoes on your feet" (LC005)

History of alcohol use

At the time of baseline interview, service users were asked if they could describe when they perceived their drinking to have escalated and whether they could identify any reasons why this happened. There were a range of responses including, childhood trauma, relationship or marital breakdowns, family bereavements, major surgery and loneliness.

One common theme throughout however was that the majority of these individuals had experienced trauma in their lives and that these traumatic events had acted as a catalyst in terms of their increased alcohol consumption. Almost all informants described how they had used alcohol as a way of coping to escape their reality.

"I was drinking very heavily just because I felt sorry for myself [due to recent major surgery] and I was working and earning good money..... I had to have a major operation... it was a shock because I took [sport] quite seriously....and I'll never forget the day when [the surgeon] said to me, oh you will never play [sport] again..... It was a shock to meI felt depressed after that and started drinking more and more...it was terrible....it had a big impact on me...I'm not an alcoholic but I hit the drink big time just as a comforter...Yeah, I don't miss drink, it just causes me problems" (LC007 baseline).

"A lot of things have happened. my wife is dead. And my son, he committed suicide, another brother died....[name] the eldest in the family, he died with [condition] and so did [name] the second eldest. [name] died with natural causes... and [name died with [condition] And my dad died with [condition] before. So, I went through a lot, it was a very hard time for me... I lost a lot of my family in a short period of time, in 10 years I would say about 7 of the family" (LC005 baseline).

"I had a difficult life, my wife was 43 when she died 27 years ago and I was left with a son and I have put all my energy into getting him sorted. He got married last year....I had a wee apartment, and I always did drink, but then I started drinking heavy and that's why I ended up here .So, it's the loneliness I thought it was going to be good; the first couple of years of my retirement was great then the inevitable happened and I started thinking, being on my own and so forth. I went into overdrive on the alcohol" (LC016 baseline).

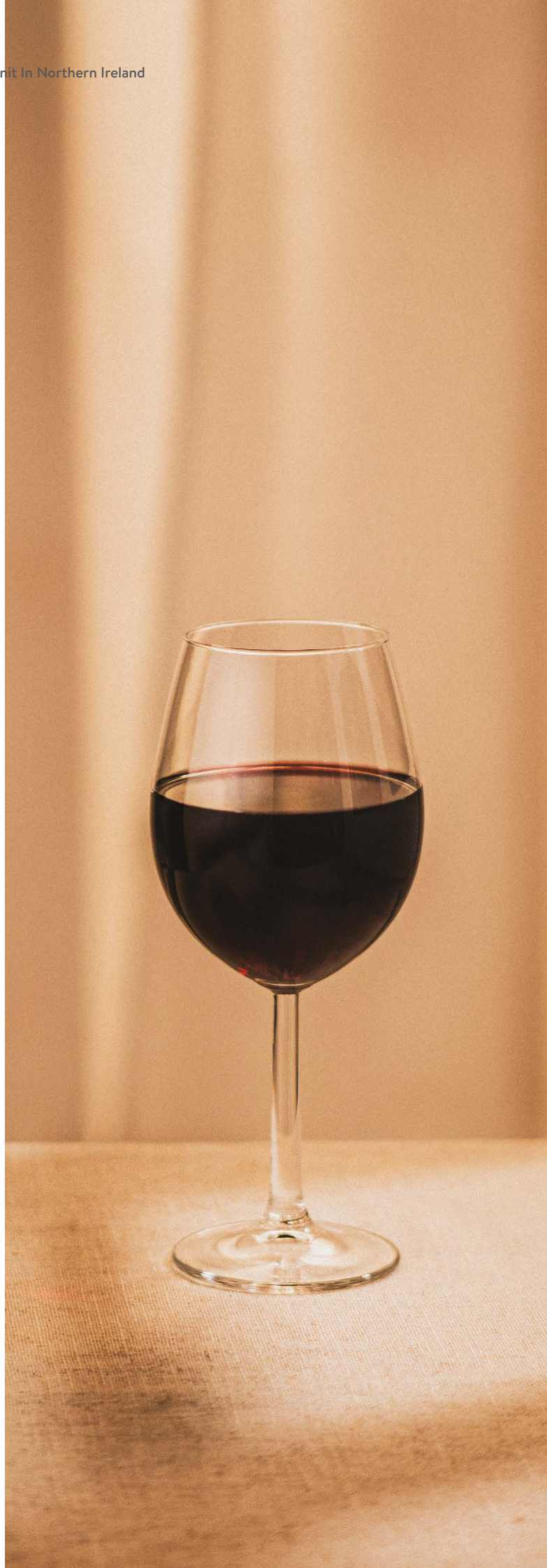
A number of service users made reference to adverse childhood experiences, including parental alcohol use, family dysfunction and loss.

“My mum and dad were alcoholics and there was always fighting and shouting and all of thatall through my childhood we didn’t get to laugh much and it wasn’t nice for us but I used to hold my hand over my sisters ears and sing to her and just rock her, she wouldn’t have heard anything.....our upbringing really affected us... My brother [name] was the same, when he lost his son he died too, just sadness, he was such a clever child and [brother] just couldn’t hack it anymore.....I think that was one of the reasons why [brother] started drinking whenever [name] died and then I started drinking when [brother] died, so it was a vicious circle. I think it got worse as it was more stress because I knew the kids were over with their dad and I was missing them and stuff. I think that sort of chain reaction happened..” (LC017 baseline).

One service user describes below how they realized that their drinking had always been problematic from a young age and it had differed from peers from the outset.

“I have always hated alcohol, always hated it.... it was my brother who handed me a glass of Buckfast and we went down to [town] and I walked to the caravan site, went into the town, fell asleep for hours, threw up and I swore I was never going to drink again...I knew from my first drink of alcohol, that was the time when I knew I was an alcoholic. I would always go out and get pissed.Then I was happy enough sitting drinking in the house on my own with a litre bottle of vodka, fags and some weed while watching Hollyoaks, Emmerdale, Coronation Street, Eastenders. So, that got a hold of me.... I had to get pissed, I mean really pissed. (LC009 baseline).

The holistic rehabilitation service aimed to address four key areas of rehabilitation for those residing in the unit. Specifically, the service aimed to improve cognitive functioning, psychological wellbeing, social relationships and community participation as well as maintaining abstinence and reducing risk of relapse. The following themes outline the service user and family/carers’ perceived impact of the service in each of these areas throughout the residents’ stay in the unit.



3.3.2 COGNITIVE FUNCTIONING

At the time of baseline interviews, almost all (19/20) service users reported having previously been in hospital as an inpatient because of their ARBI condition at some time prior to being referred to the unit, with hospital stays ranging from two weeks to over six months.

Almost all reported varying degrees of cognitive dysfunction prior to and upon their arrival to the unit, some recalling vague memories, others remembering nothing for significant periods of time and around half experiencing some degree of confusion.

“I just knew there was something wrong. So, I went up to the doctors straight away in [A&E] and then the whole year, blanked. I had thought that Christmas was over, there was the time I heard all the cheering, and fireworks and they said no you have another few weeks still. I was really confused. just all blank..I was in my house and from my house to the doctors and then to the hospital and then blanked... Then I was up here, and I still feel confused at times.... There’s been times I look across and there was a chair there and I thought I was home with my brother. It’s still a bit cloudy” (LC009 baseline).

“When I got here I just felt confused, what am I doing here? Who do I have to talk to to get out? I know where I live but then it goes in and out as quick as it comes into my head it goes back out again...I think it starting to get better these past few weeks.... Names especially, I couldn’t remember people’s names..... I’m just aware of that as well...” (LC017 baseline).

At baseline, over half of service users (n=12) noted that the most difficult aspect of residing in unit was being in an unfamiliar environment away from loved ones. This impacted on the orientation and overall cognitive functioning of residents, particularly at baseline.


“A lot of things are patchy and foggy. I am hoping if I was back in my own surroundings if you like with pictures and books, stuff that you remember from years ago that you will start remembering things or associating things. When you are lifted from your life and plonked somewhere else with a few of your own things surrounding you it’s hard. Even [having] a dress in your wardrobe you would remember wearing it to such and such’s wedding and then start to make memories and start piecing it together” (LC012 baseline).

“This is difficult, let’s not beat about the bush why we are in here. You are removed from your family, your friends and your normal life but I will be able to look back [on this experience] and say look, I went through this and every day I get up I think this is wonderful now” (LC018 baseline).

However, there were three service users at baseline who did not consider their cognitive functioning to have been affected by their condition.

“In terms of my cognitive functioning, I would be quite academic, I think I am quite intelligent, so I don’t think that has been impacted...” (LC019 baseline).

“They put you through memory tests and stuff like that... I have done remarkably well in all the memory tests... I’ve had technical tests checking my memory and I have done well in all of them. So, I don’t think my memory has been affected” (LC007 baseline).



“I swore I was never going to drink again...I knew from my first drink of alcohol, that was the time when I knew I was an alcoholic.”

Memory work

All residents participated in memory work and orientation skills as part of the rehab programme. Residents received a memory booklet upon arrival, and this was completed at least once a day with residents and 2-3 times per day, with those who required more intensive support. This work involved constructing a timeline for each service user around the circumstances leading to their referral and arrival at the unit in order to help fill in gaps in their memory and involved linking in with families to gather any relevant information. One of the aims of the memory work was to help improve insight for residents and provide them with a resource which they could refer to as and when they chose.

At the 6-month time-point, most residents described how they had noticed some improvement in their cognitive functioning; some noted improved concentration when reading, others recalled being able to remember details of TV shows, with around two thirds describing memory work to be particularly beneficial.

"I actually enjoy reading now nearly more than television. Whenever I started off doing it, it nearly took me a couple of pages to get back into the jist of the story whereas now it's not too bad, so there is progression there and I can see it myself" (LC002 6 months).

"I love making a journal. I have a wee red book and I put all the good things that have happened. Every now and again I would just reflect over from day one to the rest of it and I haven't got to the end yet but I'm hopeful..... It just lifts me when I am maybe sitting a bit lonely and thinking about the kids and stuff where I just open my journal and I read on. I have got better and better..." (LC017 6 months).

"They do quizzes most nights which basically everybody gets asked questions in teams and that tests your knowledge. It lets you know how badly the depth of the problem is because there are some things you should know, do you know what I mean. It creates awareness" (LC002 6 months).

All those residents who were interviewed at 12 months (n=6) agreed that there had been a significant improvement in their cognitive functioning since their arrival.

"In terms of clarity I can see an improvement in terms of cognitive functioning...it has been a journey, it is still ongoing but I see the light at the end of the tunnel and I suppose I have learnt from it" (LC011 12 months).

It was evident however, from the family/ carers interviews that there were still some concerns regarding the cognitive functioning of residents despite acknowledging some degree of improvement. For those service users who had been in the unit for a year, family members reported there were some remaining issues.

"His memory is still really bad so that is sort of still a concern that I have, his short-term memory, and I think that that is something that he has to live with" (LC Relative 5).

"The rehabilitation only started I would say 6 or 7 months ago, you know like all her cognitive functioning and all those tricks to try and get her to remember and she's come on brilliantly from then but am the reason that we had the row was because we were encouraging [LC012] to journal. If I come and visit, after the visit, she'll write down, [relative came and visited me and we spoke about this, this and this so later on in the evening, did [relative] come to see you ? "No she didn't haven't seen her in a while"; OK, let's look at your journal and then when she looks at that, that'll trigger something, "Oh yes, I do remember her coming now" but she refuses point blank to do that, she just won't do it. (LC relative 6).

Cognitive Functioning & Orientation Skills

In addition to memory work, residents were encouraged to engage in orientation work to enable them to recognise the time of day, their location and how to get to and how to journey to and from the shop.

"He has become more independent as far as I know, well to my knowledge he can walk to the old Castlereagh roundabout, up the Castlereagh Road and then get whatever he needs and come back again by himself which is good, I think he's able to do that. I think that's one of the indicators that they have for allowing him to come back out into the community, that he's able to go to the shop and come back on his own" (LC relative 7).

"She can now remember the route to the shop and back, that she couldn't do before, there's all different little things that she can remember. Conversation flows a lot better with her, I can see an improvement with her (LC Relative 8).

3.3.3 DAILY LIVING SKILLS

At baseline, most of the n=20 residents described how they had begun engaging in daily activities such as cleaning their room and shared spaces as well as helping out in the kitchen. These daily activities within the unit, which were on a rota basis, allowed residents to learn or refresh skills required for every day independent living and enabled them to regain some self-worth. In addition, the residents seemed to enjoy undertaking the tasks.

“I usually do some cooking, I do the kitchen and get the preparation done on a Saturday night for Sunday roast. I get all the roasties, mash potatoes, cut all the vegetables and sometimes during the week I would go and give the staff a hand to cook and prepare the food. I like having things to do....”(LC014 baseline).

“We each collectively pull in and do bit by bit, generally in pairs. The shared areas are shared activities, somebody is doing hoovering and mopping, you have to hoover and mop your floor and bathroom weekly.. So, yes hoovering and mopping, emptying the ashtrays out the back, the ones that are screwed onto the wall. (LC022 baseline).

At the 6-month and 12-month time points, residents had noticed a change in their overall functioning abilities. Through completing their daily activities as part of their rehabilitation, all residents reported that there was a notable improvement in their daily living and competence in key life skills.

“I feel a lot better, I can go down now and make a cup of tea or a cup of coffee, go outside for a chat with someone but when I first came in here I just spent my time in the room and didn't really move much.... I just had no energy...but they worked with me and I appreciate what they have done. They have got me better, well better than before anyway....Even being able to go down there and make a cup of tea is just amazing.....they would say come on down and make yourself a cup of tea and they would go down along with you and teach you how to make a cup of tea”. (LC018 6 months).

“I do the Sunday dinner, cook it and serve it and I quite enjoy doing that. It's given me a bit of freedom as well to do what I need to do to move on... I take part in most things and I quite enjoy it. I put my input in and some people agree, some people don't agree with me but that's life. I get on great with everybody, I've never had a bad word to say about anybody and just respect people and that's something you need to do to function as a person...” (LC014 12 months).

Cognitive Functioning & Orientation Skills

A key factor in rehabilitation and recovery highlighted by service users, particularly at the 12-month time point, was the benefit of establishing and maintaining a structured routine. Most residents (4/5) described how engaging in a structured routine which involved completing daily tasks and activities provided them with a sense of purpose and wellbeing.

“Hand in the air, it does work and the routine is a very good routine to get you up, you shower, you go get food and then you have to make sure your bed is made, your room is tidy, hoovered. It's a good system and it does work because you are getting up in the morning instead of lying in bed all day. It's just the routine and everybody, the staff are always asking if everything is ok with you and stuff. They are encouraging you to do things like arts and crafts....I am ready to rock to be honest, I could go out for a 10-mile walk, that's the way I feel honestly, hand on my heart.....when I arrived here, I didn't know where I was and I don't know, maybe I was in a vegetation sort of mode, I don't know, I love it in here...” (LC017 12 months).

Over half of (n=10) relatives/carers of the residents reported there to be a significant improvement in terms of the ability of their loved ones to carry out tasks required for independent daily living, specifically daily hygiene and looking after personal space.

“I think he's able to tidy his room, do his own washing, do a wee bit of vacuuming, and wash himself, I ask him what goes on when I go up on a Saturday and I don't get much, he doesn't really say much sometimes, he'll say that there was a quiz on or maybe they were watching the football” (Relative 6).

3.3.4 PHYSICAL HEALTH FUNCTIONING

Another component of the rehabilitation programme in the unit involved promoting physical health. This included establishing better sleep patterns, healthy diet/eating patterns and encouraging physical exercise. Daily exercise classes were frequently led by residents, and these were reported by all to be beneficial to rehabilitation both physically and mentally.

At baseline, over half of the residents reported feeling physically weak and hadn't exercised in quite some time prior to their arrival at the unit. They described how they experienced muscle weakness with around a third reporting physical conditions which limited their ability to do exercise. Around two thirds welcomed the opportunity to take part in the daily exercise classes within the unit.

"I was there this morning [exercise class], I'm old, I know I am, my legs, my arms and I go to the classes although it causes me pain" (LC016 baseline).

"We did exercises in here this morning, few dips and stretches, neck and all that sort of thing. You open up things that you haven't used before or in quite some time and that's very good" (LC002 baseline).

"It's getting better, my mind is getting better each and every day. I do exercises, we go into the dining room for the exercise class every day, it makes my legs stronger so it does...I couldn't walk after being in hospital for so long." (LC001 baseline).

At the 6-month time point, service users noted a significant improvement in physical functioning overall.

"My overall health pretty good at the moment. I'm able to walk independently. I'm getting exercise and there is a pretty good healthy eating diet in here and I do a bit of exercise in my room, so I am looking after myself physically as well" (LC011 6 months).

At the 6-month time point, service users noted a significant improvement in physical functioning over a

"My overall health pretty good at the moment. I'm able to walk independently. I'm getting exercise and there is a pretty good healthy eating diet in here and I do a bit of exercise in my room, so I am looking after myself physically as well" (LC011 6 months).

One resident was particularly enthused about alternative therapies and the choice of specific dietary requirements.

"Resting, having time out and joining classes, there is different things and every day you do something different so your mind is occupied, we have mindfulness, we have yoga, and we have many different sort of things to help us feel better in ourselves...even my diet I have everything like halal or kosher food they would get me the stuff I require and I am eating a lot better" (LC014 6 months).

In addition to the exercise classes, a physiotherapist also recommended specific exercises as part of the multidisciplinary input into the rehabilitation programme.

"I do exercise every day, I have my own exercises and the physio has given me a list of exercises I have to do every morning which I do..." (LC016 6 months).

Almost all family/carers noted an improvement in their loved one's physical functioning with most reporting a significant improvement in physical ability and in nutritional intake.

"His physical health at the moment is OK, it is a lot better than it was obviously before, he has the ARBI but he also has a lot of other health complications as well. If you are just talking about the ARBI, it's a lot better than before, he has recovered quite well from that, really well" (LC Relative 1).

"So, X has come on fabulously, she has come on really well, she has put on so much weight, she was anorexic before she went in there. So, I think she has actually forgot that she was anorexic, so physically she is well, it's the three meals a day and healthy meals at dinnertime" . (LC relative 1).

3.3.5 PSYCHOLOGICAL WELLBEING

Another key aim of the rehabilitation service was to promote emotional wellbeing, manage mental health conditions and build resilience and self-confidence.

At baseline, around a quarter of residents found it difficult to articulate how they felt psychologically. There was a range of responses from trepidation to frustration to generally feeling low. One resident describes below how they faced one day at a time to combat overwhelming feelings.

“I keep things as simple as possible really, there is no point in torturing myself. That’s exactly what I am trying to do, take one day at a time at the moment. I don’t know the seriousness of this or the extent of it. I am hoping someday I will be getting back to some sort of normality. I have to have that..... because you sit and dwell on these things, you think is that it? Am I going to be stuck in here for the rest of my life or in some institution type thing” (LC011 baseline).

Others articulated their diagnoses of anxiety and depression as co morbid conditions alongside ARBI.

“I suffer from anxiety and depression and felt a bit out of place or something. I think I’m here now around 6 weeks or something” (LC016 baseline).

“I have anxiety and depression, they say it is because I have a brain injury due to alcohol” (LC001 baseline).

Almost all interviewees reported an improvement in their overall mood, particularly their emotional wellbeing at the six and twelve-month time points. Residents were able to reflect retrospectively and note the improvement in their psychological wellbeing. All attributed this improvement to the rehabilitation programme and staff.

“I feel as though there has been a fantastic improvement in my mood and overall health. When I first came in, god forgive me but I was like a zombie, I didn’t know where I was or what I was seeing, what I was watching, what I was listening to. They work with you and kind of school you and they have brought me around now that I can turn around and say there is a great film on Saturday night, we will all go and watch it. Whereas a few weeks ago I wouldn’t have known what was on or what the TV was. They have done really well” (LC018 6 months).

One respondent reported that their levels of aggression had decreased markedly over a 12-month period.

“My own health compared to what it was 1 or 2 years ago, I can see it myself it has improved a hell of a lot. I’m not as sharp tempered as I used to be and I see the aggressive side of me has mellowed down again and I am beginning to function like a human being again....It’s just the environment that you are in and there is no need to lose my temper or anything because everyone is in the same boat only outside everyone is pushing and shoving and I just explode. Obviously in here with peace and quiet and I can function properly and just get on with things”. (LC014 12 months).

The majority of relative/carers agreed that there had been an improvement to some degree in terms of the psychological well-being of their loved one and attributed this to the fact that the residents were currently abstinent from alcohol, were sleeping and eating better and were in a better routine and were being cared for by the staff. Company was another factor that was identified by the relative/ carers that had contributed to improved psychological wellbeing.

I definitely can see a difference in him, 100% in the way he can remember things, the way he talks and his mood in general. I strongly believe him being dry has played a massive role in this and the only way he could have managed to stay off it and be dry was with the help and support from the staff.....being in there has also meant that he has been sleeping and eating better, taking better care of himself in general (LC Relative 12)

I definitely think that her not having access to alcohol in there has been the turning point for her, when she drank she always drank on her own and having that opportunity to sit and chat to others in there has been really helpful I feel, as I said before her eating has improved ten-fold and that’s all down to the time, effort and support of the staff in there (LC Relative 2).

There were some relatives/carers however, who reported that their family member had a complex set of issues in addition to ARBI and that it was more difficult therefore to determine a significant improvement in psychological wellbeing. These included PTSD, hoarding and eating disorders.

“Her mental health, I don’t think she will ever be well because she is still hoarding massively, she had such a huge problem with that. I had to clean her house out, it took a week, we had to hire a skip, she had stuff from 20 years. It was just crazy, but she is doing that there (in unit). She is collecting 100s and 100s of little stones and washing them with a toothbrush and leaving them all over so her mental health is not good; her hoarding has always been there...she just got way out of hand as her mental health deteriorated. Her father would have hoarded, her mother would have hoarded” (LC relative 4).

“Her anorexia, she was always very weight conscious and always wanted to be a healthy weight. Her anorexia came I think from a really bad relationship that she was in, she was being [badly treated by someone] and thankfully she doesn’t remember him. It was such trauma that happened to her that that has kind of just gone which is great but as well, it’s kind of strange” (LC relative 3).

“He would go through periods and it wouldn’t be obvious, I would have to ring the unit and say, “Look I ‘ve just come off the phone and he’s just really down, he’s really low and when he gets like that, he would self neglect, you know, he wouldn’t eat properly, he wouldn’t drink water, he wouldn’t wash so I would have to let the unit know that he is having a low mood because it wouldn’t be so obvious. He is very good at masking things, he would just stay in his room and say he is tired. But like he has PTSD and stuff as well. And so, it’s trying to balance all that out as well you know, so he does get lows as well and that’s what I worry moving forward, in how he is gonna manage that” (LC relative 5).



3.3.6 SOCIAL RELATIONSHIPS AND GROUP PARTICIPATION

Another key objective of the rehabilitation service was to encourage service users to avail of social support networks both internal and external to the unit and to become more embedded within the in-house community through participation. Residents were encouraged to interact with one another within the unit informally and through shared activities such as the weekly meetings in order to establish stronger positive social networks and increase their ability to access support and form friendships.

Engagement with other service users within the unit

At baseline, around a third of interviewees described the difficulties encountered living in a communal environment. Some were apprehensive of other residents in the first instance, as they had been used to living alone and spending the majority of their time in isolation. Moving to a shared space with 13 other residents and a staff team required a high level of adjustment.

“I am used to living on my own, so it’s hard to live with so many different people. So, coming into this is a shock, sitting in a full dining room it’s like eating out every meal time. Obviously, you don’t feel like you are going out but it’s kind of multiple people like we are in McDonalds all the time” (LC012 baseline).

“I felt a bit strange at the start because I was counting on going into my own place, so it was a wee bit strange coming into other people’s company but I just got on with everybody” (LC006 baseline).

Around a quarter of residents at baseline expressed how particularly, during the initial settling in phase, they preferred to spend time on their own in their room as opposed to mixing with and getting to know the other residents. This was due to several factors such as fear, anxiety, confusion and unfamiliarity of socialising with others.

At the 6-month time point (n=15) however, the majority of service users had settled in and had become more comfortable with their shared environment. Residents described how they had become more integrated into the group environment and had established social connections within the unit.

“When I first came in I just stayed in my room and listened to the radio or watched TV. I never bothered much, I would have went and made a cup of tea but everyone would be having a cup of tea and I would have walked past them and straight back up to the room.... I just stayed in my bedroom I was afraid I suppose and I don’t know what I was afraid of because they are all lovely people in here, whereas now I’m knocking at doors to see if anyone is going for a cup .. for a chat and it’s all down to the staff in here for bringing that out of me... I’m a lot more sociable, a lot more confidence.... I was just unsure, I was unsure where I was and stuff (LC018 6 months).

“I feel a lot more myself and I can laugh now at things whereas before I just shut myself down a bit, I didn’t want to do anything, I didn’t even want to eat at times and kept myself to myself I suppose” (LC017 6 months).

At the 12-month time point, all residents (n=6) were feeling much more relaxed with one another and some had established close friendships within the unit. There was also a consensus that there was a generally relaxed atmosphere in the unit which was conducive to a positive recovery journey.

“I’m just getting through my recovery in here. It’s lovely, it’s very homely and it feels like you have just got your brothers and sisters walking about, I now love chatting with the others in here” (LC017 12 months).

“It’s all the people [that has helped] you get on with everyone else that’s in here, I wasn’t able to have this before now as when I was drinking I was running around tearing the face off people, it was making me angry and I took it out on my family too. I have been great in here, I’m not praising myself... but it’s amazing what I have done, well I think it’s good anyway... I’ve never heard a row or anybody arguing and no fighting because it’s not good for you” (LC006 12 months).

In-house meetings

Weekly in-house resident meetings provided a formal opportunity for residents to come together and learn about current affairs both internal and external to the unit. Residents were encouraged to attend so as they could provide their own views and opinions on matters which related to the service and also keep abreast of current news. Around half of service users at the 12-month timepoint felt that these meetings were beneficial to them in terms of learning new information, having the confidence to share their opinion and also to socialise with the other residents.

“There are serious times when we are going to meetings where you have to take everything in whereas I wouldn’t have done that if I was drinking....my concentration is much better now in a group....” (LC006 6 months).

Other service users however, had issues with residents not engaging with the weekly meetings (see findings from staff interviews for further detail).

“Too few people use the opportunities to go to the meaningful meetings. I think the staff should push them into it and I’ve said that to [staff]. There is no point just seeing a few go.... to talk and stuff. There is a few in here that don’t want to [engage]...” (LC016 6 months).

“I find some of the residents are very good and some are difficult. I brought it up at the residents meeting often, it’s always the same 6 people that go to the meeting, what about the rest of them? Why do they not push them into going? They said it was up to the individual, well fair enough but if it’s a residents meeting you want to find out what is going on.....there are the same 6 or 7, sometimes 8. To me you have to attend them to find out what is happening in life because we don’t get newspapers or anything” (LC014 12 months).

One resident describes how they were not happy that only some people within the unit engaged with the daily chores and explained how attending the meeting and taking part in the rehabilitation provided them with increased self-confidence to discuss this issue with staff

“The staff have really helped me, we have been doing stuff with your mind, relaxing, breathing, they would say [name] come on down to the meetings, that was at the start, and I used to go on down. They then started to do a rota and I would do mine, people would do theirs..... There was people making up excuses, oh I’m tired and I’m going to go to bed. But 10 minutes after they would be out smoking a fuckin feg, and then when it is lunchtime, they are straight down eating their lunch and then back up. I didn’t like that, that did piss me off. So, I did start going to the meetings. This was around the first time that I have ever stood and spoke out at in a crowd. I said, you see that rota, it’s bullshit. I’m doing mine and other people are doing theirs, and there are some people lying up on their bed watching TV and laughing at us. So this place has built up my confidence and I swear I can see everything in 100% totally different from when I was on the alcohol. Now I stand up and speak and give my opinion” (LC009 12 months).

“Too few people use the opportunities to go to the meaningful meetings. I think the staff should push them into it and I’ve said that to [staff]”

Engagement/ relationship with staff

All respondents noted that their relationship with the staff played a pivotal role in their ongoing recovery. Around two thirds of respondents noted that staff treated them as 'normal' without any judgement around their condition or past and felt this was a key factor in their recovery. It was appreciated that the unit worked under the ethos of rehabilitation rather than 'control'.

"They treat you as a normal person in here, they don't treat you as someone who has got a disease or got something wrong" (LC014 6 months).

"The staff are excellent, and I get on well with them and I think that's also a good thing in here because if you were just sat in your room all day looking out the window and weren't speaking to people it would be soul destroying. I really appreciate having a chat, just general discussions about life, it doesn't have to be serious or heavy. There is a friendliness about it without being relaxed, no one is pushed too far. There is obviously a sort of discipline but I couldn't fault it..... rehabilitation seems to be the focus here rather than just controlling people or getting them through the day....."(LC019 6 months).

"There are a small number of staff, but they are absolutely brilliant, they are always very in there, it's not like they are reading your mind but they know when you are down and you don't have to say a word. They just come over and put their arms around you" (LC017 12months).

"The staff in here are decent lovely people and I would class them as friends now rather than staff. No matter what you want, even if you wanted to talk you just go down and knock the door and say can I have 5 minutes? They stop doing what they are doing straight away. I've nothing but praise for them, fair play to them it's a tough job they have got but they make it look easy" (LC018 discharge).

All residents across all timepoints, emphasised that staff were extremely helpful, friendly, and personable which, allowed them to establish rapport and trust with the team. This rapport was the anchor for service users engaging in the service, to attain an improved level of independence.

"The staff are great, they have helped me to improve and to become more independent by doing more things for myself. In the last place I was in I wasn't doing a thing for myself" (LC003 12 months).

"They would take you into town into the shops and that and the best thing about it is they leave you on your own. You could wander off anywhere but you just don't because you trust them. You put your heart into it and do what you are asked to do, even if you wanted to just go into the shop, you could walk into the shop and go out the back door and they would never know where you were but you don't do it. You trust them and you don't want to do anything to mess up that trust. I know none of the others here would do it either once we are taken out, we are looking forward to coming back so there is no chance of us going wandering. I really appreciate what they are doing because it's not an easy job" (LC018 6 months).

There was also evidence of a reciprocally collaborative working relationship between staff and the residents.

"They come to my room and they say to me X, it's your turn to do the vacuuming or whatever, or the cleaning up but I'm up like a shot away out doing it. I like helping the staff. I like being there to give them a hand because I know what they have done for me. What they have done for me is more important than Hoovering the floor. I like to give them a wee hand....." (LC018 6 months)

Some residents also praised the staff for giving them time out when needed and encouraging autonomy over their daily schedule.

They [staff] give you time out, whatever time you need or they will ask you when do you think you will need time out and you just say to them and they let you get on to do what you think is best for you (LC014 12 months)

Engagement with family and significant others

Social interaction with family and friends was also encouraged and for around a third of residents, at baseline (n=20). However, this caused some degree of distress and confusion as to what the current status of their relationship was with their loved ones. Respondents described how they feared that they had acted inappropriately because of drinking to excess prior to their arrival in the unit. Whilst some could not recall if they had damaged relationships, others were aware that they had done so and expressed remorse.

Service users noted that it would be beneficial for them to have more information regarding their condition, its severity, as well as an estimated time frame of stay in the unit.

“[I have] apprehension about going out and having to repair relationships that I can’t really remember what happened to break them down in the first place.... If someone could say to me honestly in here that right ok, you have broken a relationship with this, this and this person and these are the reasons why. I would write to them individually and apologise and if it was something I still felt strongly about I would try and get that across but not at the expense of family and friendship....., I would like to be able to stand accountable and apologise for it. At least you would know where you stand and when you come out you are starting fresh. These things happened because I wasn’t in the right frame of mind.....” (LC016 Baseline).

“They don’t tell you too much in here so you will have to work it out yourself, you know... I would like to know the whole story. Where was I? Was I behaving?..... I was in hospital for a wee while, I was taken out and, they don’t tell me very much..... You ask things but then they don’t like to tell you too much. So you are left..... I sort of want it all laid out in front of me.... You are always looking for more to make things less confusing” (LC008 discharge).

“I would like to go up to my husband but I don’t know what way he would react to that and I don’t know if he has met somebody else or whatever, I just have no clue about that area...I don’t even know if he knows I’m here....I would like to reach out to say that I am getting better... I’m sure it would lift my spirits as well.....” (LC017 baseline).

Impact of Covid on engagement with family and carers

Covid restrictions were enforced soon after the opening of the unit, and this had a negative impact on face-to-face visitations from relatives and carers, limiting opportunities for service users and relatives/carers to see each other face-to-face.

“It was not very good due to the Covid, lockdown was a nightmare so it was. There was nothing to do.... Nobody was allowed to come into the building, not even family, no visitors, I weren’t able to see my daughter, my family had to come up and drop stuff off for me and it was very frustrating” (LC001 baseline).

Throughout Covid lockdowns, staff had to improvise and arranged regular remote contact with relatives using smart devices such as iPads. This contact was greatly appreciated by the service users and relatives as it provided an opportunity for them to see each other (albeit virtually). One resident below described how they looked forward to these video chats:

“I’m getting to see my wee ones today so I am chuffed... It’s over video..... I have a brilliant relationship with my son... It’s always been the same. I have two sons, no I have three sons and two daughters. I don’t see the wee ones, but I see them today” (LC001 6 months).

Most relatives/carers however explained that they were still able to visit their relatives outside of the unit during Covid restrictions, and described this as a huge benefit:

“During Covid, we were still allowed to go, but we could go outside so they put a gazebo thing up and had like heaters and things out when it was cold. So actually seen [relative] more through covid than I do now because I’ve got a new job, so that has taken up a lot of my time. Being able to still see [relative] during lockdown made a considerable difference, it really helped both myself and [service user] immensely” (LC Relative 6).

Perceived change in relationships with family and significant others throughout their stay in the unit

Around half of residents at 6 and 12-month time points perceived their relationships to have improved with family and friends because of their time in the unit and also because they had been provided with professional help.

“My relationship with my daughters has changed a hell of a lot. I’m not grumpy, I’m not short tempered, I’m more patient and I can have a good decent conversation with them. From being in here that has helped me to improve my relationship yeah, it has improved my relationship with my girls.... It’s a different situation now and it’s 100% better than what it was before being here, it’s getting the professional help, that’s the big part of it” (LC014 6 months).

Below one resident describes how their ability to hold a conversation and communicate had significantly improved during their stay. They were engaging more with family and friends and felt that their humor had improved.

“So, say if my sister texts and says how are you doing? I text her back and then she texts me and then I text her but I add on bits and this goes on for about half an hour. Then I would phone, and she would say... I have to go here and put the kids to bed, hung up, and phoned my ma straight away Did you hear our [LC009]? holy shit he could write a book, he was speaking away and he was thinking about what he was going to say. My ma rings me then, well what are you doing? You know what I’m doing, I’m lying up here in the room with not much to do. Then I go on and on and she was choking for a cup of tea, and she loves her tea. She looked at her phone and we were speaking for over 1 hour and 40 odd minutes.... I just talked and talked. I have got funnier, I do pranks and I laugh, I say things” (LC009 12 months).

Others did not perceive any significant improvement as they felt their relationship to have been strong from the outset.

“I have a very good family and friends, my ex-wife, my daughter, so we see each other quite a lot and I speak to her every day. That hasn’t changed any since me being in here. I’m still very close to my family and my friends touch base with me as well. Maybe not on a daily basis but once or twice a week. I’m not sitting here on my own staring out the window worrying about that my life has changed so dramatically that I don’t have who I would have had prior to coming in here” LC019 12 months).

This was reiterated by around a third of relatives/carers who felt that their relationship with their relative had not changed significantly since their time in the unit as it has always been strong.

“We’ve always had a good relationship, we get on well, we are both very straight so we can clash at times. So if I say something to her and she doesn’t like it she will give it to me back but that’s the way it’s always been, we’re always good together. When I walk in she is always pleased me and likewise I’m always pleased to see her so yeah our relationship is still great yeah....” (LC Relative 2).

Participation in the outside community

Another aim of the service was to increase the self-confidence and skillsets of residents by encouraging them to become more embedded within the community. Covid restrictions had prevented residents from engaging in any external activities until mid-2021 when these restrictions were gradually lifted. Service users were then encouraged to reintegrate back into society and regain some level of independence as part of their rehabilitation. Around two thirds of residents at the 12-month timepoint reported going into the city to visit the shops and felt that this was beneficial in terms of their rehabilitation.

“Since the lockdown has been lifted me and [staff] went down to the city centre. We got the bus down there just to see what it was like and for me to be around lots of people. It was a good day, we went to TKMAXX, we went into different shops and then came back. After that I went down to the town on the Sunday myself and I got the bus down, it was good, I’m beginning to feel a bit more like a human being again. I went down to [town to see my [family], spend the day there and then came back here again”. (LC014 12 months).

“With the lockdown as well, a lot of our staff was restricted at doing things like going out to the park or for a walk, everything like that. That has been lifted now and we just went to Ormeau Park yesterday. Everybody had a good day, weather was nice and then we went after that to Dundonald and we had a game of indoor golf or whatever you call it....Then before that, we went down to the town centre to look around and get back into the routine of mixing with a different lot of people, different crowds and to see what it’s like...We have been bowling a couple of times at Dundonald....We all thoroughly enjoyed it” (LC018 12 months).

All relatives/carers (n=10) stated that their relatives had demonstrated some improvement in relation to their ability to socialise and participate both with them and within the local communities. Family members noted their improved confidence and their increased desire to socialise with others.

“He is more confident, he is definitely more confident, with talking and that. Whereas before, I would bring him down to my house and people would be here and that and he would avoid conversations but he would take part in that now, so he is definitely more confident, more vocal, definitely” (LC Relative 9).

“Confidence would be a big thing, and he’d attend a thing like Men’s Shed, social things and some kind of swimming club. I know before, he maybe would avoid things, like he joined a Men’s Shed and he experienced some racism in there but he did want to go back and try it again which I thought was quite brave of him which was really good because I wouldn’t do that. So for him to do it in his situation I thought it was quite brave. He has most definitely improved in terms of his confidence and ability and desire to mix with others” (LC relative 1).

Return to the local community

The overall goal of the service was to discharge residents back into the community to a setting that provided the greatest level of independence possible upon completion of their rehabilitation programmes. This varied according to the ongoing needs of the service users and included being discharged back into independent living in a bungalow, living with family to being housed in assisted living facilities. Around a third of residents required a level of additional support due to comorbidities and these needed to be taken into consideration when attempting to find suitable placements for residents at time of discharge.

Throughout the interviews however, service users reported a number of concerns regarding the discharge process. Over half of the service users at time of discharge (5 out of 8) reported that there were some delays around securing suitable placements for those who had completed their rehabilitation programme and were ready to move on with life back out in the community.


“I knew I was ready to leave here around four months ago but the only thing that has kept me in is that I was homeless.... It’s not their fault or anything. Years ago, if you went into jail say for about 5 or 6 weeks the [housing] executive held on to your house but now they don’t. My old house that I was in there didn’t stay empty for more than 5 days and then somebody else was in it” (LC009 12 months).

“There are very few proper decent places available to me, there seemed to be very few places about. There was one in the XXXX Road and they were looking for an over 65 who was a dementia sufferer. They are specifying you have to be over 65 which thankfully I’m not..” (LC007 12 months).

In addition, over half of the residents at time of discharge (5 out of 8) expressed a desire to live in a particular area or area of the city, according to their religious affiliation or prior occupation, which caused further delays in the discharge process.

“They were sending me to a centre, a house and it was in Andersons town and the other one was on the Falls Road. I went, I’m ex-security forces and I can’t go anywhere near there. So they have put forward another one to my son and he is going down to look at it...” (LC016 6 months).

“I just want a wee terraced house somewhere preferably in East Belfast which is where I am from and where I was educated, where my GP is.... I told them I would live anywhere in Belfast, even West Belfast. I think it’s a good community although preferably I’m from the East and I would really like to live on that side of town” (LC007 12 months).



It’s a different situation now and it’s 100% better than what it was before being here, it’s getting the professional help, that’s the big part of it

3.3.7 DESIRE TO REMAIN ABSTINENT

Another key objective of the service was to increase the ability of the service users to maintain abstinence from alcohol through the rehabilitation process. Throughout the course of the interviews service users were asked their views regarding maintaining abstinence once discharged from the unit and their perceptions of how they might manage this outside of the unit. At various timepoints throughout all of the interviews all, apart from one, expressed a strong desire to remain abstinent from alcohol upon discharge. The vast majority described how their lives had significantly improved whilst receiving support from within the unit and being alcohol free. Almost all reported improvements in their health, both physically and mentally, whilst others stated that they did not want to drink again as it was a burden on their loved ones.

“The disease is always going to be there until the day I die. I have to try and think where I was before and where I am now, and I do not want to go through that again or put my family through that again. To me it was just causing me a lot of problems and I was getting in more trouble with the law, and I was in front of the judge left, right and centre for some things that could have been avoided. I did not realise that my brain was not telling me the right stuff, it was just like my brain was controlling me and my behaviour and I had no control of it. I was not realizing the damage I was doing until I got the proper help...” (LC014 discharge).

“I won’t go back to that, I’ve had all that time for partying and now my focus is on the kids, my grandkids. My mum’s old and she won’t be here much longer and I have put so much stress on her. She didn’t need half of it you know....Alcohol gave me good times at the very start and then as it went on I started to take things the wrong way. I was out in the streets fighting, the police were at my ma’s door 3, 4 or 5 times and so yeah, I was in hospital loads and so alcohol destroyed me, alcohol put me onto death row but then being in here has saved me because you can look at the way I am. There was good times, then really shit times, rock down bottom, almost dying and now I am coming out of here breathing, far happier and alcohol free....” (LC009 discharge).

“I’m not going down that road again, because it only got me a sentence in jail I’m out of my shell now and I’m back to my old self. whereas with the drink I was just a nasty person. I can’t actually believe some of the things that I did.... It’s something I’m not proud of.” (LC006 discharge).

All relatives/carers (n=10) stated that their relatives had demonstrated some improvement in relation to their ability to socialise and participate both with them and within the local communities. Family members noted their improved confidence and their increased desire to socialise with others.



Future goals

The rehabilitation process for service users also involved goal setting, with the assistance of the clinical lead and rehabilitation team during their recovery in the unit. These goals were considered to be helpful in terms of motivating service users to look forward. At the time of discharge, (n=8) residents were asked about their future goals. These included returning to work.

“Personally, from my own point of view I don’t know if it’s realistic or not but I would hope I could work again and stuff, that’s my thinking. I don’t think I am a beaten docket yet so to speak. I know I have this condition but that’s my thinking. I don’t see myself lying in a corner quivering for the rest of my life, I think I still have more to do and every day I seem to be getting better..... I need to know where I am, I have to have an aim and I’m not going to be sitting around here for the rest of my life, that’s the way I’m thinking” (LC019 discharge).

“I would love to get back to my work, I’m a [tradesman] and I would love to when I get my energy back, and maybe so a couple of days a week and then build it up to 5 days a week. That’s something that I will do but I’m maybe not ready for it just yet energy wise” (LC018 discharge).

One respondent reported her goal was to enroll in education and pursue a career in counselling as a result of her own experiences.

“I would like to go to tech and do a course in counselling because I have received so much counselling as a result of my [operation] and stuff. I was a [XXX] manager for 6 years for a business before in [England].... I’m not going to go back into [XXX] and I’ve received so much good counselling I thought I would like to do a course on it and [XXX] Tech runs a course which started in September there but it starts at different times throughout the year..... I hope to eventually become a counsellor but I’m going to have to do that voluntarily to begin with... I feel like I would like to utilise my experiences and get some qualifications towards it and become a counsellor.....” (LC007 discharge).

Another respondent expressed a desire to return to family life and to focus on re reigniting relationships with family.

“I’m a granda now and that’s the reasons I want out of here. I want to be with my granddaughter, and I want to be involved..... And that is one of the reasons I am pushing to get out..... I still have an apartment of my own, they don’t want me to go back to the apartment on my own because they said ‘you will start drinking again’. I won’t though, I don’t intend to. I’ve got a precious little granddaughter now and my son has told me ‘if I start drinking again you won’t see your granddaughter’.... There is no doubt about me being able to manage myself, I can manage my finances, I can cook for myself, I can tidy up the apartment... I can’t do any work except the housework and so forth. I do my regular work in here and the exercise” (LC016 discharge).



3.3.8 GENERAL OVERVIEW OF THE SERVICE

In addition to addressing the background of the service users and the four specific outcomes of the study (cognitive functioning, psychological wellbeing, social relationships and community participation and abstinence), discharge interviews also captured rich data regarding residents' general views of their experience of the Leonard Cheshire service.

Comparison with previous facilities

During discharge interviews residents were asked if they had previously resided in any other facility (apart from hospital) as a result of their condition and if so, how it compared to the ARBI rehabilitation unit. All acknowledged that the Leonard Cheshire (LC) service was better suited to their needs and provided more opportunity for rehabilitation and recovery.

"A few months before here I was in [care home] which was a totally different set up. I noticed a difference [moving to unit] and I think this unit is for people that have my condition. It was a much older crowd [in care home], it was like an old people's home and there was nothing, no vibrancy, you didn't go for any walks, you didn't do anything. You got up in the morning, had your breakfast and everybody sat about" (LC002 discharge).

The LC unit was also considered to be more age appropriate for service users with ARBI and the tailored rehabilitation programmes were considered more successful in addressing the individual needs of the residents.

"In the other place it was a nightmare..... It was desperate, it was more of a residential place for people that had strokes etc.... I hated everything about it, where do you start? The individuals there if they are brain damaged by being born with it or through haemorrhages, there wouldn't have been any improvement on them from what I have seen. There was no accommodation for the individual's needs, you were just under the same blanket and that was it....In here is better by leaps and bounds because I can actually talk to other residents and the staff will actually talk to you as a human being. It's totally different" (LC012 discharge).

Residents reported that they felt comfortable and respected in the LC unit and did not feel that they were being judged because of their history. The positive, therapeutic environment resulted in the service users wanting to engage more in the service to improve their quality of life.

"I was down, where do you call that, I forget the name of the place. A recovery place in [location], you wouldn't have been able to do half the things in there.... Because you felt as if you were, how do you explain? I lasted 3 days, that's all I lasted and my son said please mum. I just said 'you are not here, I am'. Whereas in here I feel much more normal..... Nobody judges you in here, that's one thing I will say, not one person, staff member, manager or anyone. You can laugh and joke with them and I just feel comfortable and that for me has made all the difference..." (LC006 discharge).

One service user below described how having more responsibility for their personal belongings was of particular benefit.

"It's been spot on compared to the last place, it was more like an old people's home. I know most of the residents didn't have the full pack, that's the only way I can explain it. My clothes were going missing, I just don't think the staff gave a monkeys.... No one had their own shower or bathroom and so you had to book in your time for a shower and you had to be seen by one of the staff getting into the shower. It was very demeaning... I have my own shower here and my own bathroom toilet. I look after my own washing. You can nip out the back there for a smoke there is no problem there.... the staff here are dead on and it's a lot more relaxed" (LC010 discharge).

Perceived impact of service at time of discharge

For those eight residents who had reached the point of being considered ready for discharge, almost all residents reflected upon how they had regained skills for independent living and also noted an overall improvement during their time at the unit.

“I feel that I have really improved in a lot of areas, I can do my own washing, bring it down in a big sack and shove it in the machine and then put it in the tumble dryer and then shove it back in the sack and take it to my room and put it all away in the wardrobe or in the drawers. My room is immaculately clean and I clean it every day. It’s made me realise that alright, I’ve been through major [operation] and it’s stopped me playing [sport], it has interfered with my [education] but being here has stopped me feeling sorry for myself.” (LC007 discharge).

One resident reflected on how they had gained a deeper insight into their personhood and had also seen a marked change in other residents.

“You just work with them and eventually everything will fall into place but it will take time and patience on both sides, but eventually it does unlock itself and you begin to understand yourself. Really, why you are why you really are, what you have achieved and, speaking for myself, I can see a difference in me and other people as well in how they have changed for the best, how to do things for themselves.... It’s been a very good experience and it has benefited all of us since we have been here” (LC014 discharge).

Others reflected on how they had opened their minds to the recovery process and how it had allowed them to be a ‘human being’ again.

“It’s worth it for anybody who is here. Talking about myself I think it is worth it and it is enjoyable and it gives you time to collect yourself or try to remember what life was like before. A year ago I was belonging to my own little bubble, my own little world that I let no one in and no one came to see me. Now as time has went by since I have been here, I have begun to open up and I can sit and have a conversation. I join the conversation, I have been able to take care of myself, do a bit of cooking, do my own ironing, do my own washing because before that I depended on other people. In here has given me the freedom to be a human being again...” (LC009 discharge).

All relatives/carers also noted significant improvements in terms of levels of independence of service users in various domains and attributed this to the rehabilitative work the residents engaged with in the unit.

“I have noticed that [relative] has become a lot more independent which is good in terms of he is booking his own transport now to go to appointments. One of the areas, with me and my [relative] really is that he might not depend on me as much now really to book transport, in that he is now booking it for himself and that is something that I’ve discussed with the unit as a plan for my [relative]. With the issues that he has, can they devise a plan that he can address for example, helping him with transport, how to book transport and times and stuff and I can see real progress in this area which is really great” (LC Relative 3).

Overall, all relatives/ carers (n=10) reported their experience of having a family member avail of the Leonard Cheshire service to be positive. They emphasised the caring and professional attitudes of the staff, both towards the residents and the families.

“I think the staff are fantastic. I think they have a great understanding of the job but they get involved personally, so they do those personal things that is not part of their job. It’s honestly because they like what they do, or else they wouldn’t do it but the majority of staff seem to have a very good connection with (service user) and I love the way they speak to me about her, because when they speak to me, it doesn’t come across as being pompous or anything like that, you know they talk to me in a very one to one level “ (LC Relative 2).

“As far as the unit that she’s in, I think they have went above and beyond. I think, (Staff) is absolutely astounding at her job, I mean she went above and beyond with X. She went in on her days off to take X into town, to show X round the place to see if [they] would know any direction and could find [their] way home. She brought things in from her own home for her room, she stayed after work to talk to X whenever X was upset, I just couldn’t speak highly enough of her. I think the job she done was...Let’s just say, I don’t think X would be in the position she was in if it wasn’t for the input from [Staff]. And I’m singling her out because she led the team, but the team as a whole” (LC Relative 4).

The fact that the unit provided a rehabilitation service as opposed to simply managing the residents was considered to be much more preferable for relatives/ carers.

“Well obviously it’s specifically for people with ARBI so [other residential facility] was different, it was just obviously generic residential home. I think that it’s great that there is a service like this in Belfast, because it’s very limited. I think I saw 2 units before that had areas for people with Korsakoff’s and it wasn’t really rehabilitation, you know. It was just management, keeping people really, where this is more of a rehab unit which is absolutely fantastic, both for the families and for the family members” (LC Relative 8).

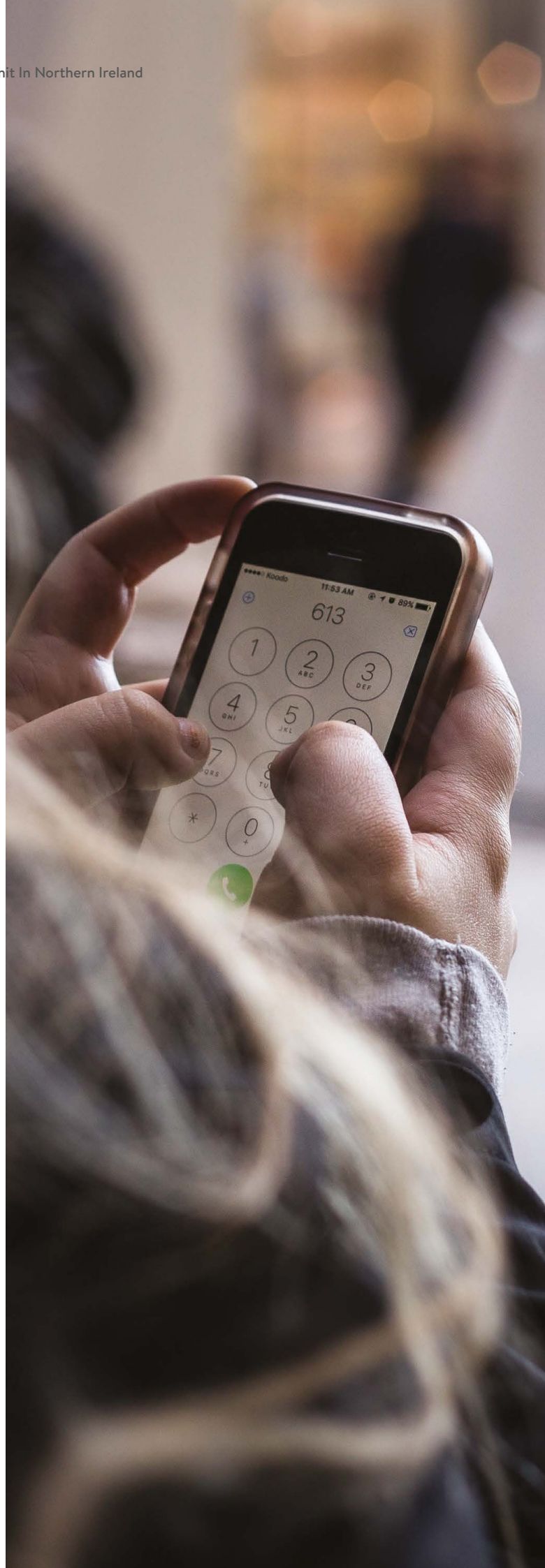
In terms of the level of communication between staff within the unit and relatives/carers, there were mixed views. Whilst the majority (6 out of 10) were happy with the level of contact they had with the unit, other relatives (3 out of 10) suggested that perhaps even more communication might be of benefit for all involved.

“I like the way, they keep me informed. I like the way that from day one, I haven’t worried. So when X was in hospital, [they] escaped five times from hospital. I was driving around Belfast trying to find X, it was an absolute nightmare. I was constantly on edge, I was in visiting every day, sometimes, twice a day, getting calls in the middle of the night, 3 o’clock in the morning, (relative) won’t settle, can you come up or can you talk to [them]? It was just a nightmare, and from day one she’s been in Leonard Cheshire, they’ve said, (service user) will be looked after and they haven’t let me down” (LC Relative 2).

“I would maybe like more updates on how your relative is actually doing. Maybe once a month or if they hit a milestone or something like that there. Because I don’t like hassling the staff very often so I ask [service user] but what I’m being told and what is actually happening...I’m not quite sure. I just take [their] word for it. So maybe regular monthly updates, how close they are to maybe being discharged and also what the options for that are, as it just seems that there should be more supported living places available for the whole scheme to work” (LC Relative 8).

“Well obviously it’s specifically for people with ARBI so [other residential facility] was different, it was just obviously generic residential home. I think that it’s great that there is a service like this in Belfast, because it’s very limited. I think I saw 2 units before that had areas for people with Korsakoff’s and it wasn’t really rehabilitation, you know. It was just management, keeping people really, where this is more of a rehab unit which is absolutely fantastic, both for the families and for the family members” (LC Relative 8).

“I am, I only think, and this is a personal opinion, and I only think that it’s because I’m very involved. I want to know everything, you know, that goes on with [relative] and I know there’s issues around consent and stuff, but I would like to know more of what’s happening or that they ask me more. For example, [relative], they think that [relative] can manage his medication but he can’t, because when he comes here and I ask him, he can’t do it. He lets on to them that he can so he says yeah yeah yeah...So can we devise a plan with a list for each week that we learn a new tablet, you know, that he takes and the side effects of it and what it’s for, and things like that? But I would like for them to work with me more and for me to work with them” (LC Relative 3).



3.3.9 SUGGESTIONS OF HOW TO IMPROVE SERVICE

Service users and relatives/carers were asked about what could be done to improve their experience in the unit. There were a variety of responses including implementing more activities, increased financial support and an inhouse tuck shop.

Increase in activities for service users

Around half of service users mentioned during the 12 month and discharge interviews that they would like more things to do during their stay in the unit, as at times they experienced boredom. Individuals who felt bored also stated that this was one of the reasons why they had previously drank alcohol at harmful levels. It was difficult for some to cope with life without drinking and experiencing feelings and emotions without alcohol. There was a general perception that ‘keeping busy’ was important to alleviate the boredom.

“I certainly get bored, I’ve been here about six weeks. It’s alright, but after a while I like to keep myself occupied and they can’t do it... I don’t know, I had my own house, it was a big house, three gardens, big bedrooms, garage and it kept me occupied” (LC016 discharge).

A few residents suggested more sports equipment for socializing together, such as a dart board, would help them to mix with one another and also help to relieve the boredom.

“We have everything that we require and if we haven’t got the stuff we can ask for it. There is a pool table in here which we got. The problem with the pool table down there is if you are 6ft it’s small...”(LC014 discharge).

“Get a dart board in, and keep the people occupied. That’s one of the things they have to do” (LC010 discharge).

One resident felt that the opportunity to complete more courses during the stay within the unit would be advantageous, for both enjoyment and to learn new skills, particularly in preparation for future employment opportunities.

“That’s what they need in here, they need courses... Because that would help and give the people something to do... I’ve always wanted to do woodwork, make a table type of thing” (LC001 discharge).

Additional financial support

It was noted by three service users at the 12 month and discharge time-points that the weekly allocated spending allowance was insufficient to cover all that they needed such as cigarettes, personal care items and taxi fares to and from frequent hospital appointments. One resident below explained how they did not want to be a financial burden on their family and felt as though they should have more monetary support.

“The family is not going to say no to you, the hardship that they are going through as well is putting extra pressure on them. They would come a long way to see us, some of them are unemployed as well, some of them are old age and that’s a burden for them..... You shouldn’t make people feel like they are a burden and the majority of us have worked for most of our lives and paid our tax and everything else. Most people would probably be on about £25 per week, what the hell can you do with £25 per week if you smoke, you need deodorant, and if you are a woman you have to get personal stuff? We are human beings as well and a little bit more would help a long way.....£25 is nothing, not if you have to pay your own taxi money to go to the hospital. Sometimes I get 2 or 3 hospital appointments and that’s £20 a journey, and you get £25. How do you work that out? They should rethink that again” (LC014 discharge).

In house Tuck Shop

All residents at the 12-month time point felt that an in house 'tuck shop' would be very beneficial or alternatively a portable shop that called once or twice a day. There was a shop within walking distance of the unit but there were a few issues for residents regarding accessing the shop when they needed to buy something. The most common difficulty was that staff were not always available to accompany them.

"When I want to go out to a shop they are always short staffed.... I would probably have to wait until the next day to get my cigarettes" (LC003 discharge).

"I asked could I go down to the shop but because they have to send someone with me, no one has come back yet... They are busy don't me wrong and it's not just me that's here, there is 12 or 13 other people... If I am waiting I keep saying to myself, what's keeping them and that's after an hour or two and sometimes they don't even come. So I am still sitting there and getting worse and worse, even if they said it would be an hour or two instead of 5 mins, you wouldn't be sitting there waiting. I would really like that improved" (LC016 discharge).

One resident suggested getting the daily newspapers delivered to the unit to enable them to keep up to date with current affairs.

"I said about getting the papers delivered every morning, they said that was a great idea but they still haven't done it and I still have to go down to the shop to get a paper. Now I can't because there is not enough staff to walk with me..... I miss out" (LC016 discharge).

Communication & Information packs

Around a third of the ten relatives/ carers agreed that more information for families regarding ARBI would be helpful. One relative suggested that an information pack would be a useful resource for families to learn more about the condition and help them understand the needs of their loved ones.

"My relationship with my [relative] can be strained, you know, its been over a long time, it's so so stressful, you know for me, I've been carrying the responsibility for him for a long time. I think information for service users and their families is a big thing, like when [relative] went in there was no literature and I know it was during Covid times but there was nothing to read, there was nothing to you know. I kind of knew about Korsakoff's before, but for somebody who doesn't know, it's like really hard to access information. So I think a package you know, for the service user going into Leonard Cheshire and for the families, of what the condition is, how it affects their behaviour. I think if families knew more about the condition, there's no information out there, there's nothing in the hospitals, nothing at all. So like an introductory information pack for relatives and also one for service users would be incredibly helpful and beneficial. Just in simple layman's terms so as people can understand the ins and outs of ARBI and what to expect. And also either family therapy or a family network, something like that." (LC Relative 2).

"I just think that more communication and just more information for people would be, even for discharge like information pack for families if they have relapse, what do they do? Because people don't know and for the service user, what do they do moving forward" (LC Relative 5).



Provision of psychological support

One relative/carer suggested that family Therapy sessions would be beneficial for both the family and the service user to express feelings and emotions in a safe environment, learn more about how ARBI was impacting on the family as a whole and how best to cope with certain situations. It was felt that this therapeutic environment could facilitate the repair of fractured relationships..


“I don’t know if was something that Leonard Cheshire want to do but you know, but having a service for families every month to come and help to build relationships again. It would just be a chance where the person with addiction, the person who is the addict does not want to hear about anything, they’re in complete denial. I did this once before in [detox facility] and it gave me a change to get everything out in a safe space and to start again and the family therapy was the best thing I’ve done with [relative]. And I don’t know if he remembers it or not but it was really good. And I just think something that bridge that gap with relationships would be really good in terms of, as much as the unit is great, it’s when they get into the big bad world, is the hard bit” (LC Relative 4).

Around two thirds of relatives/carers agreed that the addition of a counsellor to the existing multidisciplinary team would be of significant benefit to service user as this would provide a safe space for them to open up and talk about their past, any previous trauma and potential triggers for relapse. It was also seen as a core part of the care package for individuals with co morbid conditions.


“I think this is something that would be very important, you know, like Cognitive Behavioural Therapy or even Counselling. I think that some form of talking therapy is vital, it would be so beneficial for them to change their behaviour. I just think that because addiction and mental health you know go hand in hand. I just feel that it’s a gap that isn’t addressed in the unit, but it’s not going to be addressed, it mightn’t be addressed when they leave the unit you know. It’s a hard one just because you know, there’s no dual diagnosis out there’s no nothing there outside the unit so I was just wondering if that’s something that the unit does, some kind of weekly therapy with individuals, some kind of counselling or talking therapy or I don’t know, I think that would be good (LC Relative 5).

The recovery process could also be augmented by the provision of direct behavioural work to enhance coping mechanisms on return to the local community.

“I think some kind of behavioural work needs done in terms of hoarding, massively and in terms of her personal care, so X won’t get showered, wash [their] hair, or do these things without being prompted, X needs prompted to do it. And even when X is prompted, [they’ll] do it begrudgingly. So X can’t, X couldn’t live on their own. [Their] own physical health would deteriorate and [their] mental health would. So X needs some kind of guidance or behavioural help in that way to kind of you know, to encourage X to live independently as we all do, you know” (LC Relative 2).



I just think that more communication and just more information for people would be, even for discharge like information pack for families if they have relapse, what do they do?



Availability of placements at discharge

As mentioned earlier, service users had some concerns regarding the availability of placements at time of discharge. The majority of residents stated that more placements tailored to the needs of the service users were essential to alleviate their concerns prior to discharge .

“I am feeling disappointed because I was supposed to be moving out from here to a place called [XXXX] on the [XXXX] Road. For some reason I was waiting a year and a half, they were supposed to have a meeting because they are changing the law in the nursing home or whatever it is. I was told I would be moving in before Christmas, then it was after Christmas and then 3 weeks ago I was told I’m not sick enough to go to that place. That was a kick in the teeth and so now I have to start again from the bottom and to find another place. That puts a lot of pressure on one’s mind, you can’t get somebody’s hope up and then bring them down. I’ve waited for a year and I thought I was going to go and then they break it down. They should have known prior to that, that I was not going to get it so why drag it out and me along for a year and a bit? More needs to be done about this, more suitable places need to be available for us to move on....” (LC014 12 months).

All relative/carers also expressed concerns regarding the shortage of appropriate placements in the community. It was unanimously agreed that there needed to be a significant increase in the number of supported living places available for service users to bolster the positive results that had already been achieved within the unit.

“There seems to be quite a few people who are left there long over the time in which they are ready to be placed in an appropriate placement elsewhere to continue their rehabilitation in the community. That’s what I’m worried about, that it’s not the right place for [relative] and that the support’s not there when X does come out, because obviously X is gonna need some kind of help and support to reach that level of independence that they’re capable of reaching. Supported living would be ideal, you know that one to one sort of thing or one to two, but out in the community where X has a bit more freedom than [they] currently have” (LC Relative 4).

“The current provision for support living for when people get discharged, there aren’t enough placements. What’s the point of investing in this service where you bring all these professionals in to do some form of rehabilitation then to discharge these same people into an old people’s home where there is no stimulation or rehabilitation? It’s just a waste of money and I think they really need to think about that” (LC Relative 6).

“Supported living would be a realistic next step for [relative]. I got an email to say that this particular place became available in [XXX] and there would only be 4 residents and 3 staff at all times. They’d all have their own rooms, own kitchens and it is supported living so there would always be someone there. The thing that kind of put me off that it was Derry and so I was kind of then well hang on, this really isn’t about me, this is about what’s best for XXX regardless of where it is. The staff in LC said look, ‘these places are like once in a lifetime places’, they don’t come along so I would grab it. So I said, “Right ok I give my consent for her to go, brilliant “and I had emailed Leonard Cheshire to give my consent and the social worker and then I got an email three days later to say that there’s no place there and they’re now looking again. I mean what’s the point in going through all this rehabilitation to then be putting these people in an old people’s home where they are left unstimulated with these people who have all different kinds of ailments?... I’m just, I’m gutted....If they are gonna have this facility then they need more appropriate placements such as supported living placements made available” (LC Relative 2).

Outreach Service

All relatives/carers considered the outreach service to be an essential component of the Leonard Cheshire service and felt that this was an area that could be focused on in order to further improve the overall service .

“I think it’s important that people don’t just leave the unit after all this rehabilitation has taken place and go back into the community, back into the same environment where there are triggers and familiar things and they are able to do just whatever they want to do, I feel that they really need more support post discharge. I feel that more resources are needed in this area so as it can be most effective in maintaining all the progress that has already been achieved by the rehabilitative work done in the unit” (LC Relative 7).

Family members were extremely positive as regards the initiation and implementation of an outreach service.

“It would be excellent, even if [outreach service] started. Now I’m just throwing this out there, maybe at start it could be 3or 4 times a week and then if you feel that they are getting more confident by themselves, obviously reduce it to less and let them live their lives as normally as possible. I think it’s very difficult for them to be back into a familiar environment with the same things that make them want to drink without any support or input” (LC Relative 10).

“The centre creates a bubble for people who are in it, it provides a lot of therapy and rehabilitation but on the other end of things, it doesn’t provide a lot for people when they get out in terms of continued rehabilitation. D has started up an outreach service so that she continues to see the people once they’ve been discharged back out into the community, so that she can still provide a level of support in order to reduce/prevent the risk of relapse. I think this is imperative to the success of the entire project so I do, I really do” (LC Relative 8).

“The only concern of mine is X leaving there, what’s going to happen then? Because that unit really does bubble X, it really does help X in every way. They encourage X so much, X has so much encouragement there that when X moves on and X will be [their] own and X doesn’t have that...what happens then?” (LC Relative 4).

The main issue articulated by family members was in relation to what happens to my family members when they leave the unit ?




3.4 SUMMARY -SERVICE USER AND CARER FINDINGS

The qualitative findings for service users and carers were organised and presented into the following categories; socio economic history of service users, cognitive functioning, daily living, physical health, psychological wellbeing, social relationships and group participation, desire to remain abstinent, general overview of the service and suggestions of how to improve service.

- The demographics and socioeconomic background of the service users varied significantly for the service user group. Ages ranged from 40-74 years old with a mean age of 52 years. Around three quarters of residents were male. In terms of educational background and employment history, around half had little or no educational qualifications, whilst the other half had a range of qualifications from GCSE to Master's level. Some had left school at a young age to pursue employment, two had a family business, two had previously worked in professional occupations, whilst others had pursued professional trades.
- The primary reasons reported for their alcohol use problems were childhood trauma, relationship or marital breakdowns, family bereavements, major surgery and loneliness. One common theme focused on the individuals' experiences of trauma in their lives and their perceptions of how the trauma had been a contributing factor in their increased alcohol use. Almost all informants described how they had used alcohol as a method of coping, a way in which to escape their 'reality'.
- At the time of baseline interviews, almost all (19 out of 20) service users reported having previously been in hospital as an ARBI patient at some time prior to being referred to the unit. Hospital stays ranged from two weeks to over six months. Almost all reported varying degrees of cognitive disfunction prior to and upon their arrival to the unit; some recalling vague memories, others remembering nothing for significant periods of time and around half experiencing some degree of confusion. Three service users reported that they had not perceived that their cognitive function had been adversely affected by their alcohol intake.
- All residents participated in memory work and orientation skills as part of the rehabilitation programme. At the 6-month interview, (n=15) the majority of participants reported that they had noticed some improvement in their cognitive functioning. In addition, some noted improved concentration when reading, others recalled being able to remember details of TV shows, with around two thirds describing memory work as being particularly beneficial. All residents who were interviewed at 12 months (n=6) agreed that there had been a significant improvement in their cognitive functioning since their arrival. However, there was still some concern from residents' family members as regards the increase in cognitive functioning for their loved ones with three family members reporting that they did not perceive a positive improvement in the cognitive function. They viewed this as either a lack of engagement with the journal work or for one carer, that their family member may just have to live with the obvious and possibly irreversible memory loss due to the ARBI.
- At baseline, all residents reported that they enjoyed participating in daily activities in the unit. These activities encouraged residents to learn or refresh old skills required for every day independent living and assisted them to regain a sense of self-worth. At the 6-month (n=15) and 12-month time points (n=6), residents reported a change in their overall functioning abilities. Through completing their daily activities as part of their rehabilitation, all residents reported that there was a notable improvement in their daily living and key life skills. In addition, over half of relatives/ carers of the residents (n=10) reported there to be a significant improvement in their loved ones' ability to carry out tasks required for independent daily living.
- At baseline, most of the residents (17 out of 20) highlighted varying degrees of physical weakness and referred to the fact that they had not exercised for quite a long time before their arrival at the unit. Approximately one third reported physical conditions which limited any physical exercise. However, two thirds of those interviewed at baseline welcomed the opportunity to take part in the daily exercise classes within the unit. Furthermore, at the 6-month time point, service users noted a significant improvement in physical functioning overall. Similarly, all family/ carers noted an improvement in their loved one's physical functioning with most reporting a significant improvement in physical ability and in nutritional intake.

- At baseline, around a quarter of residents found it difficult to articulate how they felt psychologically. There was a range of responses from trepidation to frustration to generally feeling low. Conversely, at the 6 and 12 month junctures, all participants reported that they had felt an improvement in their psychological and emotional well-being and felt that they could reflect successfully on this continuum of improvement. Likewise, the majority of relative/carers agreed that there had been an improvement in terms of the psychological well-being of their loved ones. They attributed this to the fact that the residents were currently abstinent from alcohol, experienced a regular sleep pattern, good nutrition and a daily routine. However, some carers/family members underlined that it was difficult to see improvements in this area due to complex comorbidities, for example eating disorders and PTSD.
- In terms of social relationships, individuals initially found it difficult to engage with others either on a formal or informal basis. However, it was acknowledged that moving from a life of isolation and loneliness into a group care environment is a daunting task, with or without an ARBI. One quarter of respondents at baseline reported feelings of fear, anxiety, confusion and the unfamiliarity of socialising with others. At the six-month time point however, the majority of service users had settled in and had become more comfortable with the communal living environment. Positive attitudes towards social relations and engagement were also emphasised in the longer term, with a number of respondents having forged and sustained friendships with other residents at the 12-month juncture.
- Relationships with staff were seen as pivotal to the success of the participants' rehabilitation and increased social, physical and cognitive functioning. All residents emphasised that staff were extremely helpful, friendly and personable and this allowed them to establish a meaningful relationship with the team members, which was essential for attaining successful outcomes. The building of a trusting rapport, between workers and service users, was the anchor for service users engaging in the service and to attain the agreed goals and an improved level of independence.
- For some respondents, the thoughts of future engagement with families was particularly concerning, as some individuals harbored feelings of remorse and fear about the consequences of their drinking for close family members. Covid restrictions throughout the first half of the research fieldwork stage also proved difficult for family communications, although this was ameliorated to some extent via the use of online communication platforms. At the six (n=15) and 12-month (n=6) junctures. Approximately half of participants at each time point perceived their relationships to have greatly improved with family and friends throughout their time in the unit. A number of residents and a third of carers reported that relationships had not necessarily improved simply because they had always been strong and continued to be so throughout their time at the unit.
- Whilst Covid restrictions referred to above limited interaction with the community outside the unit, many respondents engaged with external activities when restrictions were eventually removed. Four residents reported that they enjoyed visiting shops in the city centre and taking a walk, activities which they felt were beneficial in terms of their rehabilitation. All relatives/carers stated that their relatives had improved in terms of interaction skills, both with them and within local communities.
- At the discharge interview (n=8) service users were asked their views about maintaining abstinence once discharged from the unit and their perceptions of how this might be achieved. All, apart from one, expressed a strong desire to remain abstinent from alcohol upon discharge. The majority of residents at the 6, 12 month and discharge timepoints reported that they had experienced improvements in their health, both physically and mentally. Whilst others reported that they did not wish to return to drinking alcohol due to the consequences for their family members. Person centred work with residents also focused on the setting of agreed goals, which were considered to be helpful in terms motivating service users to plan ahead as regards their return to the community. At the time of discharge, residents discussed their future, including return to work, enrolling in courses and spending quality time with family.
- Residents at discharge also compared their stay at other facilities, including hospitals and care homes with their residency within LC. The majority agreed that the unit was more age appropriate, provided autonomy and had ultimately helped them to gain a sense of self and prepare them for the return to their local community. There was also a consensus as regards the respect that was afforded to the service users in the LC facility. Respondents did not feel judged because of their history, which was hugely important for all participants. It was also noted that the positive, therapeutic environment encouraged the service user to fully engage in the service.

- All relatives/ carers (n=10) reported that their family members had a positive and therapeutic experience within the unit. They underlined that the staff were doing much more than simply 'caring' for their loved ones and were overwhelmed as regards the level of cognitive, social, physical and psychological changes in their family members as a direct result of the therapeutic regime. However, there were mixed views about the level of communication between staff and relatives/carers. Whilst the majority (6 out of 10) were happy with the level of interaction they had with the unit, other relatives (3 out of 10) suggested that perhaps even more communication between unit staff and family/carers would help all parties involved in the therapeutic milieu.
- Service users and relatives/carers were asked in all interview phases if anything could be done to improve their experiences in the unit. There were a variety of responses, most of which were focused on practical assistance and ways to increase activities and improve facilities. For example, a number of residents mentioned the boredom that often happens when one stops drinking and therefore there was a need for some to access as many activities as possible. Some suggested a full size pool table, dart board, and more practically an inhouse tuck shop for ease of access to small non-perishable goods, such as tobacco and newspapers.
- Around a third of relatives/carers agreed that more information for families regarding ARBI would be helpful. One relative suggested that an information pack would be a useful resource for families to learn more about the condition and how best to help their relative and how to best cope themselves as a carer. In addition, service users noted that it would be beneficial for them to have more information regarding their condition, its severity as well as an estimated time frame of stay in the unit.
- One third of families/carers highlighted that more psychosocial support should be made available for families/service users via family therapy and for participants though the provision of in house counselling CBT or behavioural therapy.
- A theme consistently referred to on several occasions throughout the interviews was in relation to the inadequate number of suitable placements for people leaving the unit. It was reported that there were some delays around securing suitable placements for those who had completed their rehabilitation programme and were ready to move on with life in the community. The delays were compounded in situations where respondents expressed a wish to live in certain areas in Northern Ireland. When service users and family members/carers were asked what improvements could be made, there was a consensus that this really should be a priority issue.
- Likewise, it was deemed important that an outreach service should be implemented to help sustain the successes achieved in the unit for service users and family members.



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SECTION 4: FINDINGS FROM STAFF INTERVIEWS

This section presents the findings from the staff interviews and is structured around the following themes; factors that facilitate service implementation, challenges to service implementation, perceived impact of the ARBI service and what is needed to improve and sustain the ARBI service.

4.1 FACTORS THAT FACILITATE SERVICE IMPLEMENTATION.

All staff agreed that overall, the ARBI rehabilitation service had been successfully implemented within the unit. Although, as with any new service, there had been a few issues that needed addressed during the first year (see section 4.2). However, we begin below with factors that staff felt facilitated service implementation and improved outcomes for service users. .

Availability of placements at discharge

A supportive, positive environment was considered to be one of the most important factors in facilitating the rehabilitative work with service users. Staff described how most service users had arrived at the residential facility after having experienced chaos in their lives due to excessive drinking with little or no social support. Their drinking behaviours had often escalated as a result of trauma, which in turn had led to poor coping strategies and a breakdown in relationships. Establishing a supportive therapeutic environment was therefore considered to be vitally important by all staff in order to allow the residents to feel safe .

“I think just a really caring approach. A lot of these people have had trauma in their lives, so I think just having a safe, caring environment with your basic level of support, I think that is really important” (LC Staff 1).

It was noted by one member of staff that this supportive, safe environment was very evident within the unit and that the dynamics and cohesive nature of the team were responsible for this.

“You are coming into this environment, potentially by yourself, you know.....It’s just that environment, that positive environment which is great, So I think that makes a massive difference and even going back to the place I was before, when negativity starts to creep in, all the residents had conversations with me and were themselves picking up on it and feeling down because of the negative atmosphere. I think that is something that we just don’t have here. It can’t be taken for granted because it’s about staff cohesiveness, consistency and commitment (LC Staff 5).

“It’s a lovely team, a lovely ethos within the unit and a good atmosphere whenever you come in, everybody wants the best for the residents. I think it’s really important to have that safe environment in which everybody feels comfortable in. The atmosphere, the safety of the unit, the security and routine and most of all the staff” (LC Staff 1).

All interviewees agreed that the mutual support that staff had for one another and for the residents was really important in the success of the service. Although staff had their individual allocated tasks to complete, ultimately the team were very supportive of one another and offered each other help and support.

“I think we have got something good going on here now, we seem to be very much in sync with each other in that yes, we have our allocations in the morning but if something’s not done, it’s not like, right [staff] hasn’t done that, so we all do muck in. Just because your name is against that doesn’t necessarily mean that you just have to be doing that, so I think it’s quite good that way and the staff support each other” (LC Staff 4).

As well as staff establishing a close working relationship with one another, it was also considered key for the staff team to establish trust and rapport with the service users in order for the service to be effective. All respondents emphasised the importance of this relationship in facilitating the engagement of residents with their individual rehabilitation plans. This therapeutic relationship provided much needed emotional and social support, which had often been lacking in the lives of the service users prior to their arrival at the unit.

“So here the residents have often exhausted relationships with family and relatives. Here they have our unconditional support, if they have a slip up or are having a bad day and are shouting and screaming, we are still going to be here for them the next morning, so I suppose it takes a while for the residents to get used to that. That initial settling in phase for the residents is always difficult as they are thinking, we will see if you are still around when I do such and such, so it’s nice for them to feel like they have support here and that they are safe” (LC Staff 2).

Basic self-care skills

Upon admission to the unit, service users were subject to a comprehensive multidisciplinary assessment to establish their individual level of need. Referrals would also be made to other services as required, for example, Psychiatry, Dietetics, Optometry and Dentistry. All staff emphasised the importance of starting with fundamental self-care tasks such as, getting out of bed, getting washed and dressed in the morning, following a healthy diet and establishing a normal sleep pattern. It was agreed that it would be futile to attempt rehabilitation in other areas such as cognitive functioning, home management or vocational rehab if the individual was unable to meet their own basic self-care needs.

“I think it’s the back to basics, you know, have a shower, just strip it right back, you know, don’t put too much demand on them” (LC Staff 4).

A structured routine

All staff respondents emphasised the importance of creating and maintaining structure in partnership with service users and explained that this routine formed the foundation for all rehabilitative work to build upon.

“I think that routine element is so important, as a staff team, we don’t let up in a professional and in a supporting way. If somebody is not taking part in their routine on a daily basis and there are goal plans and rehab plans in place and everyone here is so driven towards wanting to help these guys so every day it is about following that routine and making sure that they are getting up in the morning. We have seen individuals come in here before and they’ve had no routine in the past and are up every morning getting showered and things of that nature, it seems so small potentially to you or I, but it is actually a massive hurdle for them to get over” (LC Staff 3).

It was evident that ongoing, consistent rehabilitation work was conducive to the recovery of those residing in the unit. This rehabilitation work was individualised to suit the needs of each individual based on ongoing assessments by the rehab team and other professionals from the multidisciplinary team [see section 1.3 for details]. As well as personal care, the structured process within the unit involved teaching residents basic life skills, for example, managing money and financial tasks, preparing meals and laundry chores in order to promote autonomy and independence.

There was also the feeling that rehabilitation was a continuum of in-house therapeutic support and not simply reliant on a series of specific appointments with peripatetic therapists.

“I suppose it’s really pushing that idea forward that we are not just here to make sure people are fed, watered and safe, but actually having that focus that we are here to improve people’s lives. For everyone that comes in, there’s that push, can we get that person to a stage where they can live in the community again independently? It’s very much that ethos of rehab, not waiting for the physio to come in at 10am or psychologist, that’s great that they come in but the rehab is happening all day long. That’s when you make the difference, not when a therapist comes in and spends an hour with them, it’s whatever else we do, the rest of the day” (LC Staff 2).

Residents were also encouraged to set realistic and achievable goals (with the assistance of staff) and each person had a specific set of aims and objectives tailored to address their individual needs.

“Obviously, things to be individualised for them as well. Every resident is different and each resident has a very different profile as well. So having different approaches is going to be really important as everyone has their own set of goals that are specific to them and that is personal for some people as well. People have very different backgrounds and very different goals that they would like to achieve as part of their rehab so that’s really important too. The clinical lead, along with each resident will set personal goals” (LC Staff 1).

Cognitive Rehabilitation


In addition to the work focused on daily living skills, mindfulness groups and memory work, executive functioning and orientation skills were also part of the rehabilitation programme for each of the residents. Staff described how service users were provided with a memory book upon referral to the unit. The booklet was completed everyday with the residents and even more frequently for those with significant cognitive deficits. This work involved constructing a timeline for each resident around the circumstances leading to their referral and arrival at the unit in order to help fill in gaps in their memory and involved linking in with families to gather any relevant information. One of the aims of the memory work was to help improve insight for residents and provide them with a resource in which they could refer back to as and when they chose to do so.

“We also do a lot of memory work with the residents also, that’s a memory booklet that we complete with residents as they come into work on their diagnosis and how they got here. Usually with a lot of our residents have a gap on how they got here, so we do some work around putting a timeline together for residents and whenever they ask those questions such as: How did this happen? How did I come to be here? We have got some concrete evidence by linking in with families, this is something we do quite a lot there as well. Some people find it difficult to take that information on board, a lot of our residents have difficulty with insight and things like that and when they ask those questions we will redirect them back to their Memory Booklets...” (LC Staff 1).


“ We have a couple of individuals who couldn’t remember anything from one hour to the next when they came here and again that routine and doing the memory work with them a couple of times every day really helped. You can physically see the progress that they are making and I think a lot of it is down to that routine and memory work and that’s backed up by the staff here”(LC Staff 5).

In addition to the memory booklets, staff described how cognitive rehabilitation also involved relearning orientation skills. Strategies used to help residents with their orientation skills included memory prompts such as Alexa’s orientation clocks, calendars, post-its, diaries, whiteboards, and smartphones. As service users’ orientation skills improved, the number of prompts were diminished to help prepare the service user for their return to the community. *“We also do a lot of memory work ” It’s about trying to remember X children’s names, how to describe them, where they live, who her siblings are, where they are living and once that’s repeated over a period of time, it sort of sticks, it’s remembered then. Then we will change the questions once we know that X has grasped that and it’s something X didn’t know moving in here, X now knows that, we will take that question out and add a different question in about something else that has happened in [their] life and it’s building on [their] insight which is really good” (LC Staff 3).*

All interviewees agreed that the memory and orientation work proved to be of significant benefit to the residents in terms of improving their cognitive functioning and recall.



“We have a couple of individuals who couldn’t remember anything from one hour to the next when they came here and again that routine and doing the memory work with them a couple of times every day really helped.”



4.2 CHALLENGES TO SERVICE IMPLEMENTATION

Staff were also asked about the factors (if any) that hindered the initial implementation of the model. As with any new service, staff reported some minor issues that became apparent during the initial few months of the service going live. Some of these issues were resolved relatively easily as staff became more familiar with their roles, the new residents and the service as a whole. These issues are described below.

Impact of Covid

The ARBI unit opened approximately two months before the first COVID lockdown in Northern Ireland, in March 2020. All interviewees agreed that the resulting safety restrictions enforced in all residential settings throughout the UK posed a significant challenge for the staff team and service as a whole. Staff described having to adapt their way of working to comply with covid safety regulations and how this resulted in less of a focus on the rehabilitation component of the service, particularly during the initial lockdown phase. Attention shifted from engaging the residents in socially rehabilitative activities to a primary focus on ensuring the safety of individuals. In addition, staff were getting to know each of the residents as individuals as well as attempting to settle into their new roles and responsibilities within the unit. This was a new staff team that were still getting to know one another as well as trying to establish how to operate as a team most efficiently in order to achieve the best possible outcome for residents.

It was evident that the first few months following the launch of the service was an extremely difficult and challenging period for all involved.

Despite these unprecedented challenges, staff described how the team worked together to ensure the safety of the residents and to meet their basic care needs. In addition, staff soon managed to begin implementing the individual rehabilitation work as best they could, with the available resources and within the confines of the unit.

None of the transitional multidisciplinary team were allowed to visit the unit during the initial lockdown stage and all of the rehabilitation assessment and formulation of individualised plans had to be completed by the core ARBI team based within the unit.

Covid restrictions also prevented service users from having any opportunity to leave the unit with friends or family or engage in or attend any community group or social activity. This resulted in the community participation component of the rehabilitation service being significantly delayed until restrictions were eased in mid-2021 (however, there had been some engagement with the community established in the 3 months period prior to lockdown). Only essential work by Physiotherapists for risk management of falls was prioritised throughout lockdown. As restrictions eased, staff reported that the team moved quickly to establish links with appropriate external community organisations and residents were actively encouraged to get involved. Transport for the residents was provided by the unit.

During the lockdown phase, staff described how they had to adapt to the crisis and had set up a virtual visiting service for residents to see and talk with family and friends using a tablet device. Although this wasn't the same as having regular face-to-face visits, it proved to be popular with the residents and staff reported that service users appreciated these virtual calls.

In addition to the memory booklets, staff described how cognitive rehabilitation also involved relearning orientation skills. Strategies used to help residents with their orientation skills included memory prompts such as Alexa's orientation clocks, calendars, post-its, diaries, whiteboards, and smartphones. As service users' orientation skills improved, the number of prompts were diminished to help prepare the service user for their return to the community.

Staffing issues

In addition to covid related concerns, it was clear from the interviews that there were some staffing concerns from an early stage. These concerns became evident soon after the opening of the unit in January 2020 as demands on staff time and resources turned out to be significantly greater than was initially envisaged in the planning phase. All staff agreed that additional staff would be beneficial to the service.

“At the start we were realising that things maybe weren’t as straightforward, and I guess it became clear very quickly that staffing levels and things like that hadn’t been adequate and very quickly we needed to request more. I think initially, we only had one person for overnight and that wasn’t sufficient. . The first year was definitely a learning curve because what was on paper maybe didn’t quite match what was reality, as to be expected, additional staff and additional funding would make a huge difference, we are doing what we can with what we have available to us” (LC Staff 2).

One staff member described how staffing levels could at times negatively impact on the opportunity for service users to leave the unit and engage in the community participation aspect of their rehabilitation.

“Staffing can be an issue sometimes also, getting people out into the community [post covid restrictions] so that’s maybe something we can look at... Some days we are under staffed and we just have to do what we can do” (LC Staff 1).

Extensive administrative work

The extensive administrative work related to logging and reporting of the daily rehab activities for each individual proved quite burdensome for a number of staff. It was suggested by one staff member that perhaps a computerised system, with the use of an iPad, might help to alleviate this and allow more time for staff to engage in the rehabilitative work.

“You’ve got your memory work, therapies going on, one-to-ones, exercise classes. You’ve all of the above going on and you have to document all of that on a daily basis. It would be amazing if we could have a computerised system because a lot of the staff’s time is taken up with writing and writing so it’s just so busy” (LC Staff 6).

Suitability of referrals

Staff reported that there had been a few issues regarding the suitability of some referrals to the unit, and this seemed to be a particular concern during the initial year. However, this has become less of a concern as the service has become more embedded and those involved with the referral process have developed a better understanding of the purpose of the unit:

“Certainly, during that first year, we were going out to screenings and we were thinking, no, that’s not for us. But now, things have settled and people seem to understand the purpose of the unit and it’s not just another nursing home to put people in, it is a rehab unit, people will be here short stay, it’s about moving people on” (LC Staff 2).

It was considered an imperative by all staff that service users demonstrated rehabilitation potential for the service to be effective. For those individuals who did not want to change their drinking behaviour and engage in the programme, the rehabilitation process proved difficult.

“I suppose that just making sure that people have rehabilitation potential is important and are in a place where they are going to engage with us and open to the rehabilitation process so as we can work with them and get them to a place where they will be ready to move on. If somebody doesn’t really want to stop drinking it can be very hard to motivate them and engage them in the rehabilitation so it’s just important to make sure that there is rehab potential with people that are coming in” (LC Staff 1).

Complex traumas and co morbidities

Another concern noted by staff was that the residents often had a history of significant trauma and at times the team were unaware of the specifics of past traumas. One interviewee stressed how important it was for the team to be aware of this information in order to inform their therapeutic practice and future decisions regarding appropriate discharge plans etc.

“Getting to know the residents is important from the rehab side of things. It’s all well and good rehabing these guys but when you look at their individual stories, the majority of them have sat by themselves and drunk and got drunk....we all know that addiction comes from trauma or something that has happened in their past. We get to know wee snippets of their past but sometimes you don’t get to know actually what has ever happened” (LC Staff 6).

Size of building

The suitability of the current building was a concern that was raised by almost all respondents. Whilst the building may have seemed fit for purpose during the set-up phase, it soon became clear that it was not sufficient to meet the current demands of the service. Some reported that the inadequate size of the building was a major stumbling block in terms of how the service is currently being delivered. The unit does not have clinical space in which to conduct multidisciplinary assessments with residents in a private and sensitive manner. It was reported that the designated lounge area for residents to meet and socialise was also having to be used for meetings, care management reviews and staff training. The dining room, which was meant to be a protected space for meal times, was being used for therapy sessions. As a whole, it was agreed that these designated communal spaces for residents should be protected and used specifically for their designated purposes and that there should be additional space available for therapeutic sessions with residents as well as designated space for staff use.

“This unit, the house that we are in, I don’t feel that it is big enough to meet the purpose and to meet the needs of what we and the residents really need, for example, I had to speak to a care manager in the hallway down there, before I came up to the meeting because we had an interpreter in with one of our residents in the lounge. You are doing you’re bits and pieces in this lounge today, there were two staff members in the staff room having their break which of course they need a break and [another staff member] was in with somebody from the transitional team in the wee office down there. So the space in here is just shocking...”(LC Staff 6).

“It’s a huge stumbling block for us, for things to be holistic. You need space, you need to have a wee bit of personal space that you can share with people. Look at that there on the floor, it is being used as an Art Therapy room, space is a huge stumbling block for us” (LC Staff 5).

The lack of communal space in the current building was noted to have impacted on residents’ ability to interact and socialise with each other, particularly in the evenings and one respondent described how this had resulted in residents staying in their own rooms. The opportunity for social interaction is an important component in terms of rehabilitation of residents as it provides opportunity to interact and learn new social skills for relationship building to form friendships and to provide peer support to one another. This was considered to be particularly problematic during COVID when there were no opportunities to socialise outside of the unit. It was noted however, that this had become less of a concern for staff as residents are now able to avail of opportunities external to the unit.

“We find that a lot of the residents take themselves to their room in the evening, especially in the evenings, but as we have progressed, and we have brought in therapies and we have been able to do more outings now that Covid has gone away for the meantime, the residents have been able to get out more to Cedar, Inspire and lots of different wee things opening up now. It’s not as bad as it was during Covid” (LC Staff 5).



Protective environment/ risk of relapse

The residential rehabilitation service aims to provide a safe therapeutic environment for service users. The emphasis on protection and safety is essential to provide a supportive space in which service users can begin to establish a structured routine, trusting relationships, and abstain from alcohol. Staff interviews highlighted that whilst this protective environment is essential and conducive to the recovery of service users it also poses a significant problem once residents leave and return to the community. During their stay there was structured routine and ongoing intensive therapeutic support in an environment where alcohol was prohibited. The service users had succeeded in abstaining from alcohol for a significant period and had learned to function without it. Upon discharge however, they were confronted with the same familiar triggers regarding alcohol without the supportive framework provided within the unit. This exposure to stressors and lack of structured support put them at significant risk of relapse due to their underlying addiction. It was unanimously agreed that further outreach support in the community was required.

Staff also highlighted that the process of having to move from the unit to another potentially new location was unsettling and stressful for the individuals. Additionally, they faced the daunting challenge of having to re-establish themselves within the community by making new friends, perhaps finding a job (if appropriate), managing their own finances and establishing a new routine for themselves. These changes are significant stressors for the average person to try to cope with and significantly intensified by potential cognitive dysfunction and history of trauma and alcohol use.

“I think we are giving them a false sense of reality, you know, we don’t have alcohol here, they know it can’t be brought in. They know if it is brought in there will be room searches and things but whenever they go out into the community they don’t have that level of protection so it’s a bit unfair that we offer this security net here and then when they go back into the community they don’t have it. Hopefully the outreach service will transition that a little bit. They can walk to the shop and there is an off licence very close to us, it hasn’t been a significant issue certainly to date but that’s because staff will know if I have drunk. If I was at home, would anyone know, would I see anyone from week to week?” (LC Staff 2).

All interviewees agreed that the service should also have an input from addictions professionals to help address service users’ alcohol dependence and learn new ways of modifying behaviour and responding to stressful situations in a more adaptive way. To date, this service has not been in place and it was considered to be a significant gap in current service provision. (addressed further in subsection 4.4).

“It’s a false sense of security that we are offering them here so it’s easy for us not to focus on addiction because it’s not an issue here whilst they are in a protective unit. So I would acknowledge that we do have a lot more work to do around the addiction side of things and what that looks like going back into the community” (LC Staff 2).

Lack of information regarding ARBI

Some interviewees noted a general lack of understanding of ARBI amongst health professionals.

“In terms of some of the other community services that we have referred individuals to, their understanding of ARBI is not there, they genuinely don’t know what it is. I have spoken to addiction liaison nurses in an acute hospital who have said to me very openly, ‘tell me something about this, I don’t know what I’m meant to be discussing with the family here, so I suppose it’s a learning curve for me also’. People have not heard of it, it’s not out there. Korsakoff’s syndrome was known as Alcohol Dementia, and it’s not a helpful term because people think if it’s alcohol dementia there is no rehab. As it’s alcohol related brain injury there is potential for recovery. Certainly historical terminology hasn’t helped, as it suggests there is no rehab potential but there is and we need to get that message out and we need to help improve people’s understanding” (LC Staff 2).

Stigma at societal level

The lack of awareness and information available regarding ARBI, by professionals and the public likely contributed to the perceived stigma at a societal level, which was noted by a number of respondents.

“I believe there is a huge misconception out there that that those people with ARBI are just down and outs, the type of people that the community has closed the door on and doesn’t want to look at and actually that’s not the case. There are a lot of middle class individuals that are just about teetering on the edge or if not have fallen in the direction of dependence/ addiction. Certainly the background of the residents here in the unit, you know, it’s not people who that are generally unemployed and have been previously living on the streets. It’s people that have had a higher level education, that have been in reasonable employment and things have just gone horribly wrong somewhere along the way and they have found themselves in this position. And I don’t think this is the general public’s or even some health care staff’s perception of these individuals, it’s stigma” (LC Staff 2).

Staff also noted that a significant number of service users presented to the unit with co-occurring disorders including alcohol and mental health problems. At times this proved challenging due to the complexities of co morbidities for example, bipolar disorder, depression, OCD and alcohol.

“Often there is a mental health background there, there are co-occurring disorders and these are complex and challenging to treat at times”. (LC Staff 2).

There was also a ‘shunting’ between mental health services and brain injury services and this led to people often falling between both services.

“Historically these people would have been referred to us and there would be a tug of war between mental health services and brain injury services. The brain injury services would’ve been saying ‘we can’t work with them because they have mental health issues’ and the mental health services would have been saying ‘we can’t work with them because they have a neuro issue’ and they just would’ve been pushed between the two posts. If I’m quite honest they didn’t get offered a service in the end that was fit for purpose whatsoever” (LC Staff 4).

Issues related to discharging patients

Staff described how the Trust had responsibility for making decisions around placements following discharge. This caused some degree of frustration as staff felt that recommendations regarding placements were not always implemented by the Trust.

“The Trust released her into her house after us doing a discharge plan. We recommended that she didn’t go home. She went home to be supported by [relative], who we think has maybe a learning disability herself” (LC Staff 6).

Shortage of assisted living placements

The purpose of the residential ARBI facility was to deliver short term residential rehabilitation for service users for periods of between 12 weeks and three years, depending on the outcome of their ongoing multidisciplinary assessments. After the residents completed their individualised rehabilitation programmes and, depending on how much progress they had made in regaining independent living skills, they were considered as ready to restart their lives in the community in an appropriate placement according to their needs. At the time of interview, around half the residents within the unit had completed their rehabilitation and were deemed eligible for discharge. However, a shortage of placements prevented an efficient turnaround of beds in the unit and created a ‘bottle neck’ preventing the arrival of new referrals. This caused some frustration amongst the team who were actively trying to engage around half of the residents in rehabilitation work, whilst those who had completed their programmes had disengaged.

“The discharge rate, the turn-around. It really holds a lot of people back as it can really affect the other residents. We have a few residents who are done and have completed their rehab and the other residents sort of take

the attitude, will why should I do that because they’re not doing that? They’re not doing that because their rehab is finished. So, it can have a negative impact on the other residents in the unit. Whenever everybody is doing the same thing, now they might be at different stages and different levels but whenever everybody is doing it, they are more inclined to take part in it and things work better” (LC Staff 3).

The shortage of placements was considered in part due to COVID with related restrictions creating a back log. Another notable difficulty with securing appropriate placements was finding one in the ‘right’ area. Religious affiliation or background of residents was also reported to be important in securing a suitable placement.

“[Staff from Trust] were in the other day just talking about one of the residents and we did discuss that [assisted living facility] you know, over in the Falls Road but it wasn’t deemed suitable because of the background of [service user] I know it’s on the Falls Road but it’s sort of on the border of Protestant and Catholic” (Service User 6).

In addition to the shortage of appropriate creating a back log of discharges there were other issues noted by staff such as significant delays in getting benefit packages in place. One interviewee reported that there was a resident within the unit who had been waiting for more than six months for a benefits package to be put in place before moving to independent living accommodation.

“From our point of view, the biggest thing is that it’s out of our hands, there is nowhere for these guys to go really. I would say that maybe half the house at the minute could really be moved on elsewhere and that’s all the different locations. So we’ve one individual who is waiting for their benefits to be sorted out to go to their own home but that’s been since the start of the year, so that’s the guts of six months this has been getting discussed and there was a date that was more or less given around 3 months ago so it’s waiting for that to come to fruition and then individuals just waiting for the right place” (LC Staff 5).

4.3 PERCEIVED IMPACT OF ARBI SERVICE

Current LC service vs previous provision for ARBI

Staff described how prior to the opening of the ARBI residential rehabilitation facility in January 2020, individuals with a diagnosis of ARBI, would typically have been placed in care home settings. All staff considered this previous standard care approach to be inappropriate considering the age of those referred to the Leonard Cheshire facility. Only two of the residents who took part in the study were over the age of 65 years¹. Typically, the minimum age limit of those living in a care home setting in Northern Ireland is 65 however, there are often people below that age inappropriately placed in these settings.

“There wasn’t a lot of services available for people with ARBI, it would have most likely been a care home setting which isn’t very appropriate for a lot of our residents. We have residents here ranging from 40 years upwards. To be in a care home for the rest of your life if you’re 40. When I think of a care home it is somewhere that people go to die, and to be there for the rest of your life and for your mental health, that would be very detrimental, Whereas, with this model, it gives people hope, there is something to work towards” (LC Staff 1).

“There are guys still out there that are not receiving appropriate treatment. They go in to hospital and they are just existing, they are just being given medication and more medication where it is not medication that is needed it is actual physical rehab. In here there is a strict set routine, we get up, you get ready, we do our memory work, we do our activities, your physio exercise, OTs come in, you’ve got your workshops” (LC Staff 3).

Perceived impact of service

Overall, staff believed the service to date had a positive impact on the outcomes of service users. Significant improvements had been perceived in almost all of the residents in terms of cognitive ability as mentioned earlier. Staff reported that residents’ cognitive functioning steadily improved throughout their stay in the unit and they attributed this to a number of reasons. Abstinence from alcohol played a major role, proper nutrition and sleep cycles as well as medication. The rehabilitation work regarding memory and orientation was also perceived to play a major part in the improvement of cognitive function.

All interviewees reported that having this support enabled them to improve in areas such as self-care, improve physical strength, increase confidence and self-esteem.

“We’ve seen such a change with X. I remember when I first started, a year and a half ago, X was really confused and X was struggling with the most basic of things such as getting dressed in the morning, even using the bathroom appropriately, things like that. . Whereas after [their] period of rehabilitation, X was so much better. I remember...X would make jokes with me because [they] remembered [personal details] and X remembered everybody’s name and you could have a proper conversation with X, remember details, X made brilliant progress. For [them] the outcome has been brilliant” (LC Staff 1).

Psychological well-being was reported to have improved to varying degrees for all residents. Staff largely attributed this to abstinence from alcohol, having a structured supportive environment and being able to note their progress in terms of achieving their set goals.

For those who had previously been frequently involved with the criminal justice system or admitted to hospital as a result of their excessive drinking and chaotic life, staff reported that there had been no hospitalisations and no involvement with the criminal justice system. All staff agreed that the service has had a considerable positive impact in these areas and considered this to be a significant successful outcome for the service, the judicial system, the health care system, the community and most importantly for the service users.

“ I suppose the key one for me was one of our residents came from the prison services and there was significant push back from the trust on that one. They didn’t feel that that was an appropriate spend, they didn’t think that that was an appropriate person as this person had been in and out of the justice system and actually that person excelled here, they’ve done fantastic. Had we not really advocated for X, that would have been someone who they would have decided it wasn’t worth putting money into, as X was perceived as someone who had already drained the system from being in and out of hospitals and prisons”. (LC Staff 2).

4.4 WHAT IS NEEDED TO SUSTAIN AND/OR IMPROVE THE SERVICE?

Additional input from multidisciplinary staff

As part of the interviews, staff were asked what was needed to improve the service moving forward. There was a consensus that there needed to be additional input from various multidisciplinary staff and that it would be particularly beneficial for the service if some were based within the unit as part of the core staff team.

“I would love to have the clinical staff here, I’m not saying that we would need them on a full time basis, but the transition team that are being brought in, it’s great that we have that budget there but it’s down to when they’re available and people’s other job roles and things so from my perspective it would be great to have a small clinical team here, it would be great to have a psychologist on site” (LC Staff 2).

Input from addictions professionals was considered to be a matter of priority for the service in order to address addiction issues.

It was envisaged that the additional input would provide service users with much needed specific information, support around relapse prevention skills and more adaptive coping strategies in response to potential triggers. It would also provide a safe space in which to discuss issues and concerns around addiction and how it had impacted the lives of service users.

“It’s a false sense of security that we are offering them here so it’s easy for us not to focus on addiction because it’s not an issue here whilst they are in a protective unit. So I would acknowledge that we do have a lot more work to do around the addiction side of things and what that looks like going back into the community” (LC Staff 2).

To date, the focus of the rehabilitation service had largely been on the cognitive impairment element of the condition and how best to utilise resources in order to achieve positive outcomes for service users in terms of cognitive, social and functional outcomes.

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To date, the focus of the rehabilitation service had largely been on the cognitive impairment element of the condition and how best to utilise resources in order to achieve positive outcomes for service users in terms of cognitive, social and functional outcomes.

“The issue here is that these people have addictions plus the cognitive impairment, it’s a niche marketWhy are we offering a cognitive brain injury service for ARBI without somebody from addictions? It doesn’t make sense...we would need someone from addictions, from either mental health or nursing and that person would need to be core staff, not someone that is brought in, sessionally. It needs to be someone in the unit, it needs to be an ongoing theme in the building and reinforced on a daily basis...”(LC Staff 1).

It was noted by some staff that the service had made previous attempts to address the addiction element of the ARBI condition. During the initial set up phase there had been discussions around involving Addiction NI but due to the Covid pandemic, this did not happen. Piloting the SMART Recovery intervention was also initiated. However, due to the cognitive limitations of the ARBI condition, it was not deemed suitable for all service users.

“We had started doing the smart recovery, but it was put on hold because people here had ARBI so with the SMART recovery, we were having to recap what happened in the last session, they weren’t necessarily retaining that information so I think that that’s kind of being looked at which is good because they are here and because they have an addiction, obviously” (LC Staff 4).

In-house AA meetings were suggested as a potential way forward, by one interviewee. Hosting an AA group within the unit was perceived to be potentially more suitable than a community meeting due to the complexity of ARBI and the associated cognitive and social dysfunction. An intervention, in house, which provided a safe space in a familiar environment was highlighted as a possible approach

“I think that anyone that has a lifelong addiction or has had an ongoing addiction needs to have an ongoing support service like AA meeting or something like that but however, a lot of our guys would be very anxious going out and sitting with other people that they don’t know so even if we were to have something like that in house if someone was to come in an run an AA meeting and see if the guys would be feeling up to it. Now one week you might get 2 down who are really engaged in it but to try and encourage them whilst they are in here because the chance of relapse when they come out of here, studies show that it can be quite high especially anybody going to independent living or assisted living. Anybody who is going into residential care seem to be doing really well but those who go into independent living seem to relapse at some point...” (LC Staff 3).

It also was suggested by some staff that the addition of an activities or engagement manager would be beneficial for the sustainability of the service going forward as this was an area that had been impacted by covid restrictions as mentioned earlier. Since the lifting of restrictions, staff had been making efforts to establish links with community organisations and residents had been engaging in activities in the community. To date these included, ‘Men’s Sheds’, ‘Tools For Solidarity’ and computer classes for those who wished to attend. It was felt however, that a dedicated member of staff whose role was to focus solely on this particular area would be of significant benefit.

“I think a gap that comes to mind is an ‘Activities/ Engagement officer’, someone to have a link between getting the guys out to do a bit more, having that one individual even on a part time basis, couple of hours a day just trying to find that connection to try and get the guys out in the community more. I think from our point of view, prior to this opening, it wasn’t really thought of, that we need to actually run a service being Team Leads and Rehab Assistants, we can’t always put the hours in to developing that side of things..... we have to look after the individuals on a daily basis, their medication appointments and all that sort of thing so sometimes finding that time to establish that link in the community is not easy.... (LC Staff 3).

Another suggestion for improving the current service was the addition of a counsellor. One interviewee felt this would be of significant benefit to service users due their histories of trauma and addiction.

“There are guys here with mental health issues and sometimes you don’t think that you are saying the right thing and maybe counselling could be brought in even to deal with their trauma and where it all started. Your addiction and your mental health go hand in hand and so therapy would be very beneficial” (LC Staff 4).

Step down unit

Staff reported that there had been some discussions with the Housing Executive around the possibility of adding a step-down unit to the service for an additional three-month upon completion of the rehabilitation programme. All interviewees agreed that this would be of significant benefit for the service, in terms of further facilitating the recovery of service users and also to improve the efficiency of the service and turnover of residents. A step down unit would encourage the utilisation of independent living skills and offer support from the unit and the outreach service, albeit in a less structured fashion.

“if we had a step-down unit could move in there, you can come and go as you please and you would have to do your own cooking, not like in here where you have food provided. They will also do their own meds unless they need care assistants to come in and administer their meds but the likes of their cooking and their washing, they would have to do all that independently. It is literally like sheltered living. So, if they are waiting on a house from the Housing Exec or a space in assisted living so we can have our turn around here, but they are not stuck in limbo here. So, they’ll learn their independent living skills again here, they’ll move out, but they’ll still be within our team, and they’ll still have the outreach, and they’ll still have that support from us but more freedom then whenever they move out it’s not so overwhelming” (LC Staff 3).

“We need a step-down unit. We have individuals who are out in the community that have gone downhill as soon as they’ve got out and one day potentially they might get themselves to a point where they’ll be back here again and they’ll just keep going in that vicious circle as they’ve nowhere else to go....but with the addition of a step down unit, they will have more independence than they do here and they’ll still have routine and structure and they would still have the goals that we have in place but just potentially to a lesser extent. ” (LC Staff 5).

Importance of outreach service

Staff reported that after a six-to-twelve-month period post discharge, there was a significant level of relapse. In response, Leonard Cheshire set up an outreach programme in October 2021. It was recognised by the organisation that participants required a high level of ongoing care to support improvement after they leave the safe, protected environment in the unit. The purpose of the outreach service is to provide high quality specialist support to service users transitioning from residential settings to the community. It also aims to provide rehabilitation in relation to daily living tasks including personal, domestic, recreational, and social tasks for individuals within the home and the community. In addition, it supports individuals to attain their full functional potential, maximize options available and encourage choice, participation, and motivation and to support individuals to maintain abstinence. The outreach service also aims to work closely with the ARBI unit as well as Trust Addiction services and Physical Disability Care Management Services.

It was evident throughout the interviews that there was a significant need for ongoing support for service users post discharge to reduce the risk of relapse outside of the protective environment of the unit.

“Within the unit..... it’s a very safe and protective environment but once people go back into the environment in which they came from, it can be very easy to fall back into old habits which is really unfortunate for some of our guys that that has happened” (LC Staff 1).

“It will be interesting to see how the service users do, with the support outside of the unit now available to them. The focus should be more on the long term and better decision making and coping skills of the service users. I think it’s something that does need looked at and funded. In the longer term it would be cost effective to implement the outreach long term so as to avoid relapse and a potential long-term hospital stay. People need support and it’s a big change going from living in a rehabilitation unit to living at home. People develop routines and they will have triggers around them, triggers to drinking and to be able to manage all of that is going to be really hard. The stress of being discharged on its own, and stress can be a big trigger from someone with addiction issues so it’s going to be really hard” (LC Staff 1).



4.5 SUMMARY - FINDINGS FROM STAFF INTERVIEWS

- Interviews were conducted with six members of staff from the team housed within the LC Alcohol Related Brain Injury Unit. The staff interviews captured views on the implementation of the model as well as their perceptions of strengths, and weaknesses of the service, challenges to service implementation, perceived impact of the specialist inpatient intervention and what is needed to improve and sustain the ARBI service.
- All staff (n=6) agreed in general, that ARBI rehabilitation service had been successfully implemented within the unit, although, as with any new service, there had been a few issues that required amendment, particularly during the first year of implementation.
- A supportive, positive environment was considered to be one of the most important factors in initiating and sustaining work with service users. Staff described how most service users had often arrived at the residential facility after having experienced chaos in their lives due to excessive drinking and often had little or no social support. Establishing a supportive therapeutic environment was therefore considered to be vitally important by all staff in order to allow the residents to feel safe and secure. There was also a consensus that a cohesive and collaborative team environment was important for staff as this ultimately had a positive impact on the interaction with clients.
- Similar to reports within the service user findings, staff emphasised the critical objective of establishing a symbiotic and trusting rapport with residents and family members/carers.
- Staff also underlined the importance of re-learning basic self-care skills of washing and dressing in the morning as the starting point for a basic, structured routine for the day ahead. All respondents emphasised the importance of implementing and maintaining a well-balanced schedule which formed the foundation for any future rehabilitative work. As well as personal care, this involved teaching residents basic life skills, for example managing money and financial tasks. It also involved restoring practical skills, for example, preparing meals and performing laundry tasks to promote autonomy and independence.
- One aspect of cognitive rehabilitation focused on the use of a memory booklet which each resident received upon arrival at the unit. This work involved constructing a timeline for residents around the circumstances leading to their referral and arrival, to help fill in gaps in their memory. It also involved linking in with families to gather any relevant information.
- In addition to the memory booklets, staff utilised strategies to help residents with their orientation skills including memory prompts such as Alexa's orientation clocks, calendars, post-its, diaries, whiteboards, and mobile smartphones. As service users' orientation skills improved, the number of prompts were diminished to help prepare the service user for their return to the community. Like the responses from service users and carers, workers agreed that the tools were particularly effective in working with service users.
- The onset of the first lockdown proved to be the primary challenge during the initial phase of the unit's implementation. The aim to employ rehabilitation methods whilst introducing structure and daily skills was thwarted due to Covid and instead the main focus was to maintain the safety of the residents in the light of government restrictions. During the lockdown phase, staff set up an online communication service which proved to be popular with the residents and staff reported that service users looked forward to these virtual calls.
- There were also some concerns about staffing levels. All worker respondents articulated that more staff should be employed to ensure the optimum experience for the service users. Likewise, administrative tasks were perceived as overly burdensome and often hampered the direct work with residents.
- All staff respondents alluded to the fact that it was difficult to work with people who were not motivated to change and who were not ready for rehabilitation. For those individuals who did not want to change their drinking behaviour and engage in the programme, the rehabilitation process proved very difficult.

- Staff were concerned as regards the underlying traumas that were often overtly apparent to the worker, but at other times there was an absence of detail in relation to some of the traumas experienced by the clients. For individuals who presented with complex co- morbidities it was clear that staff were frustrated with ‘shunting’ service users between mental health and brain injury services. This process had prevented some of their clients accessing the help they required in a timely manner.
- The suitability of the current building was a concern that was raised by almost all worker respondents. It was agreed that the building was prohibitively small to meet the current demands of the service. Indeed, the unit did not currently have clinical space in which to conduct multidisciplinary assessments with residents in a private and sensitive manner. The designated lounge area for residents to meet and socialise was in fact being used for meetings, care management reviews and staff training. It was accepted that the communal spaces for residents should be protected and used specifically for their designated purposes and that there should be additional space available for therapeutic sessions with residents.
- After the residents completed their individualised rehabilitation programmes, they were not expected to take part in rehab activities within the unit. At this stage, most were ready to resume their lives in the community and required placements/accommodation tailored to their needs. At the time of interview, approximately half the residents had completed their rehabilitation but were still living in the unit. This was preventing an efficient turnaround of placements and thereby preventing new referrals from obtaining a bed in the unit.
- Staff felt there was a lack of understanding of ARBI among allied health and social care staff. This was associated with a high degree of stigma at community, cultural and structural levels, primarily due to a lack of information, awareness and education.
- Staff described how most individuals with a diagnosis of ARBI who required care, would typically have been placed in care home settings. All staff considered this approach to be inappropriate primarily due to average age of those with ARBI who had been referred to the Leonard Cheshire facility. Ninety one percent of respondents in the current study were under the age of 65 years.
- Staff reported how residents’ cognitive functioning improved steadily throughout their stay in the unit and they attributed this to several reasons. These included abstinence from alcohol, proper nutrition and sleep as well as consistent medication. The rehabilitation work regarding memory and orientation was also perceived to play a major part in the improvement of cognitive function. Another area of significant improvement for residents was in their overall functioning. Staff reported how they encouraged residents and provided visual and verbal prompts when necessary to get showered, dressed, and take part in their daily activities.
- Psychological well-being was reported to have improved to varying degrees for all residents. Staff largely attributed this to abstinence from alcohol, having a structured supportive environment and being able to note their progress in terms of achieving their set goals.
- There had been no hospitalisations and no resident involvement with the criminal justice system for members during their stay in the unit. All staff agreed that the service has had a considerable positive impact in these areas. They considered this to be a significant successful outcome for the service, the judicial system, the health care system, the community and most importantly for the service users,
- There was a consensus that to improve the service moving forward there needed to be additional input from various multidisciplinary staff based within the unit as part of the core staff team, specifically in relation to the inclusion of substance use professionals and counselling services. It was agreed that this input would need to be on a long-term basis and would require a substance use programme that recognised the specific difficulties of working with cognitive dysfunction.
- Staff reported that there had been some discussions with the Housing Executive around the possibility of adding a step-down unit to the service for an additional three-month period for residents upon completion of their rehabilitation programme. All interviewees agreed that this would be of significant benefit for the service, in terms of further facilitating the recovery of service users and also to improve the efficiency of the service and turnover of residents. It was anticipated that those residents who had completed their rehabilitation work could potentially reside in this facility for a maximum of 12 weeks which would encourage the utilisation of independent living skills but would still offer support from the unit and from the outreach service, albeit to a less structured degree than was offered during their time residing in the unit.

SECTION 5: SUMMARY AND CONCLUSIONS

5.1 CONCLUSIONS

The study explored the effectiveness of an ARBI rehabilitation treatment modality within an inpatient unit in NI. The study considered whether the ARBI treatment service improved (psychological, functional, social, and relational) outcomes for patients. The quantitative element focused on measuring the impact of the intervention on psychological well-being, functional ability, familial and social relationships/ community participation/cognitive ability and maintaining abstinence. A range of psychometric measures were used to assess psychological well-being, functional ability, familial and social relationships/community participation/cognitive ability and maintaining abstinence at base line and at five junctures throughout the project time frame.

It also included a qualitative exploration of service user lived experiences over 16 months within the unit. Qualitative service user data was collected over 4 timepoints; baseline (n=20), 6 months (n=15), 12 months (n=6) and at discharge (n=8). Remote interviews were also conducted with family members (n=10) to capture their lived experience and views. Staff interviews (n=6) focused on perceptions of the implementation of the model as well as their perceptions of strengths, weakness and benefits of the service and external influences that might impact on its implementation and effectiveness.

Predisposing and Contextual Factors which Impacted on the Recovery Journey

Respondents made reference to a number of predisposing factors which had an impact on the service users' recovery journey prior to admission to the unit. These included various traumas, previous hospital admissions, engagement in the criminal justice system and experience of other care environments. Additional contextual factors inherent to the positive development of the worker/service user relationship were cited as the 'immediacy' of the therapeutic environment and the initiation of a trusting rapport between workers and residents from the outset.

Almost all service users stated that they had used alcohol to 'escape their reality'. Most service used alcohol to numb the pain as a result of a single trauma event or persistent traumas experienced throughout the course of their lives. These included ACEs, relationship breakdowns, bereavement, major surgery and extreme isolation and loneliness. Staff also highlighted the underlying traumas overtly referred to by some service users.

However, there was also a degree of staff concern as regards the absence of information in relation to some service users who could not provide detail about their past negative experiences. It was perceived that the lack of knowledge could have an adverse effect on the building of

a meaningful therapeutic relationships.

All service users made reference to previous hospital admissions (which ranged from two weeks to six months) and /or in-patient social care admissions. Service users explained that they felt respected by the staff in LC and they emphasised that they were not judged for their medical or social history. They also reported that this was not always the case in previous encounters with inpatient care. Staff also noted that most respondents would have experienced residential or nursing care homes which were not always appropriate for the under 65 age group. They alluded to the fact that there were still a substantial number of people with ARBI in NI who continued to be placed in care home facilities, where they are not afforded the specialist care as offered by LC.

Reports from all respondent groups cited the positive therapeutic environment that was at the core of the ARBI unit. All relatives/carers stated that the staff were not only 'caring' for their loved ones but were actively and therapeutically engaged with them at all times, which was achieving excellent results for their family members in treatment.

“Almost all service users stated that they had used alcohol to ‘escape their reality’. Most service used alcohol to numb the pain as a result of a single trauma event or persistent traumas experienced throughout the course of their lives.”

Moving from Incapacity to Stabilisation, Participation and Possibility

Psychological well-being

Results from the psychometric tests (MPA1- 4, Adjustment Scale), which considered psychological well-being, indicated that there was no significant difference in scores between baseline and the different timepoints. Similarly, there was no significant change in HADs Depression scores across all junctures. However, there was a significant decrease in HADs Anxiety scores between baseline and Time 2 at three months, with a large effect size, suggesting a decrease in anxiety symptoms between baseline and twelve weeks juncture.

Staff from within the unit felt that the ARBI multidisciplinary holistic approach had a positive impact on the majority of residents' psychological well-being throughout the period of the study. They viewed that this had largely been as a result of the holistic therapeutic approach, abstinence from alcohol and the services users' self-appraisal of their goals and objectives. Views from family members also highlighted the improved psychological outcomes over the same period and they attributed this to improved sleep, good nutrition, a daily routine and abstinence from alcohol. Whilst service users found it difficult to discuss their psychological status at baseline (some respondents referred briefly to frustration and low mood), their interaction and discussion improved considerably from Time 1 to the 6 month and 12 month follow up interviews. Service user respondents reported an increased awareness of improvements in their psychological and emotional well-being.

Cognitive Function

Cognitive function was also measured using the ACE 111 and the RBAN scales for cognitive functioning. There were significant differences in ACE scores across time, with the scores being significantly higher at T2 (large effect size), T3 (large effect size), and T4 (large effect size), compared to T1, suggesting improvements in cognitive abilities. The RBANS scores did not change significantly from T1 to T3, but there was a significant increase in the scores from T1 to T4 (large effect size), suggesting an improvement in cognitive functioning.

Likewise, almost all service users also referred to a movement from cognitive dysfunction to varying degrees of cognitive improvement over time; at the beginning of their stay many had difficulty in remembering what had happened prior to being admitted to the unit. However, positive results were declared by all those interviewed at the 6-month junctures with reference to an increased focus to watch TV or to read. The greatest improvements were reported at the 12-month junctures with the most significant positive results for improvement in cognitive functioning. All residents had participated in staff facilitated memory work and orientation skills as

part of the rehabilitation programme. As service users' orientation skills improved, the number of prompts were decreased to prepare the individuals for return to the community. In addition, service users reported that as time progressed in the unit, abstinence from alcohol was a contributing factor to their cognitive improvement. At discharge interview, most service users stressed the desire to maintain abstinence on re-entering their respective communities.

Staff agreed that residents' cognitive functioning had improved enormously through the course of the 18mth period and they reported this as a result of good nutrition and stable sleep patterns together with staff engaging clients with memory work and orientation skills.

Physical function

The MPA1-4 Ability subscale did not change significantly between T1 and T3, but there was a significant decrease in the scores between T1 and T4 (large effect size), and also between T1 and T5 (medium to large effect size), suggesting an overall improvement in physical function.

At baseline, over half of the twenty-two service users reported a degree of physical health problems and seven stated that they could not perform exercise due to physical limitation. Family and service user cohorts reported on improvements in physical functioning of service users at the 6-month juncture. It was also noted by a number of service user participants that they had not performed physical exercise in quite a long period of time before admission to the unit.

Social Relationships

There was an improvement on the MPA1-4 Participation Index, with scores decreasing significantly from T1 to T3 (medium effect size), from T1 to T4 (large effect size) and from T1 to T5 (large effect size).

Social relationships showed a significant improvement across the research timeframe. All service users had moved from a place of isolation, loneliness and having little formal support to an unfamiliar, group care environment, which some initially reported as frightening and leading to anxiety, confusion, and distress. However, a more positive situation was reported at 6 and 12 months as individuals had become a more comfortable with the structured communal living and indeed some had established friendships with other residents.

It was also clear that some residents were fearful of reconnecting with family members due to their own disruptive behaviours as a result of excessive alcohol consumption. There was some trepidation as regards communicating with family members due to remorse and fear of recrimination.

Life-skills and self-care

All residents were particularly appreciative of the ongoing life skills training and enjoyed the individual and communal activities which were arranged in collaboration with staff. They emphasised that this encouraged them to learn new or revisit old skills, necessary for independent living, whilst enhancing self-esteem and self-worth. All staff reiterated the absolute importance of encouraging basic self-care skills as part of a structured daily routine. This involved personal care, finance management and daily household tasks and all were viewed as an integral part of the therapeutic rehabilitation process.

Shortage of assisted living placements

All respondents were asked to provide their views on what improvements could be made to the service. Responses focused on the following:

1. Staff highlighted that Psychosocial services including specific substance use counselling, family therapy, behavioural therapy and CBT could be provided by external multi-disciplinary staff. However, service users and staff highlighted that at least one psychotherapist could be in situ as an integral member of the core team.
2. Staff also alluded to the suitability of the building due to lack of space and reported that the premises should be expanded to address the needs of the service users and staff. For example, it was agreed that communal areas for residents for service users should be protected and that additional space for therapeutic work should be provided.
3. Staff were also concerned as regards the overly burdensome paperwork and stressed that this needed to be streamlined for maximum efficiency and to ensure that optimum time was spent on the rehabilitative work. This was also related to staff time pressures and workers reported that this could be alleviated by the employment of additional staff.
4. In addition, it was clear that workers expressed some concern as regards the suitability of some of the clients for the unit; particularly those who did not wish to change their drinking behaviour.
5. Service users called for additional activities and more resources to be made available to them, for example a full-sized pool table, a dart board and an in-house tuck shop. These seemingly small additions were deemed necessary to alleviate what was seen as the inevitable boredom that was often experienced when changing to an alcohol-free lifestyle.

6. Service user and family members requested additional information on ARBI, its effects, and how best they could help their loved ones. Service users wanted to know more about their diagnosis and how it affected them and an estimated time frame of stay in the unit.
7. All respondents referred to the difficulties that were associated with discharge. Service users referred to the waiting time for a suitable placement after individuals had completed their rehabilitation process within the unit. Staff mirrored the concerns of service users and family members as they underlined that it was difficult to engage with individuals in the post rehabilitation stage within the unit as they waited for a suitable placement. At the time of staff interviews over half of service users were in this position and had remained in the unit due to a shortage of placements.

Staff called for a step-down accommodation to be implemented as soon as possible to address the discharge backlog within the unit. There had been some preliminary discussions with Northern Ireland Housing Executive regarding the possibility of establishing a unit. It was suggested that participants who had completed their rehabilitation could reside in the unit up to a maximum of 12 weeks with support provided from the newly established outreach service. However, to date, no support has been given for the step-down unit due to lack of funding.

Staff also reported that an outreach service would be useful to provide a support system and continuity of care for individuals who returned to the community. After a six-to-twelve-month period, post discharge, it became apparent to LC staff that there was a significant level of relapse for programme participants when they were discharged from the residential unit to the community. Therefore, in order to facilitate reintegration back into the community for this population, and to establish links with appropriate organisations to prevent relapse, the Leonard Cheshire set up an outreach programme in October 2021. It was recognised that participants required a high level of ongoing care to support improvement long term after they leave the safe, protected environment within the unit.

5.2 LIMITATIONS

Limitations included the impact of Covid, which delayed qualitative data collection in the unit. The project was due to begin in the Spring 2020 and the first lockdown period commenced mid-March 2020. It was difficult to access the individuals due to the restrictions and the research fieldwork was also delayed over the subsequent lock down periods.

The quantitative aspect of the project employed a repeated measures design at the baseline and over a period of time up to 18 months. It was difficult to obtain a consistent number of assessments at the 12 month and 18 month follow up periods.

The qualitative and quantitative phases utilised relatively small samples, however, this is an exploratory study in what is the first rehabilitative unit for ARBI in the island of Ireland.

5.3 RECOMMENDATIONS

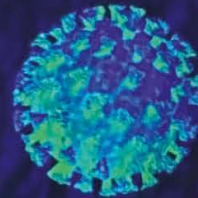
- There should be a focus on increasing the availability of assisted living placements and the development of a Step-Down facility to facilitate the transition from discharge into the community.
- The current outreach service could be extended to include community referrals for cases where people do not yet require hospitalisation. The aim of this initiative would be to significantly reduce the number of individuals with ARBI requiring inpatient treatment and to reduce cost for NHS. In addition, the additional scaffolding from an extended outreach service would further reduce the risk of individuals become involved with the judicial system.
- The current outreach service should be extended to the preventative end of the treatment continuum in order to reduce the number of hospital in patients with advanced liver problems/cognitive problems.
- It would be useful to incorporate an input from an addiction professional for two days per week through a part-time post based in the LC unit. Likewise, increased psychosocial support should be made available for families/service users via family therapy and for participants through the provision of in-house Counselling, CBT or Behavioural Therapy.
- The LC unit building should be expanded to address the needs of the service users and staff, as currently the lack of adequate space is having an impact on some aspects of the service user recovery journey.
- Paperwork and administration duties must be streamlined for maximum efficiency and to ensure that optimum time is spent on the rehabilitative work.
- Additional information on ARBI should be made available to family members and carers. Service users were anxious to know more about their diagnosis and how it affected them and to be provided with an estimated time frame of stay in the unit.
- The evidence which highlights the success of the unit should be used to support the establishment of at least two other units in NI to serve the Southern, Western and Northern Trusts.
- Further research should be commissioned to explore the efficacy of the new LC outreach service as it has been welcomed by staff and service users as a method of strengthening the successes obtained during their stay at the unit.
- Further research should also focus on estimating the nature and extent of ARBI in NI. It should also ascertain how many people under the age of 65, who have been diagnosed with ARBI, are resident residential or nursing care homes in Northern Ireland.



HM Government

NHS

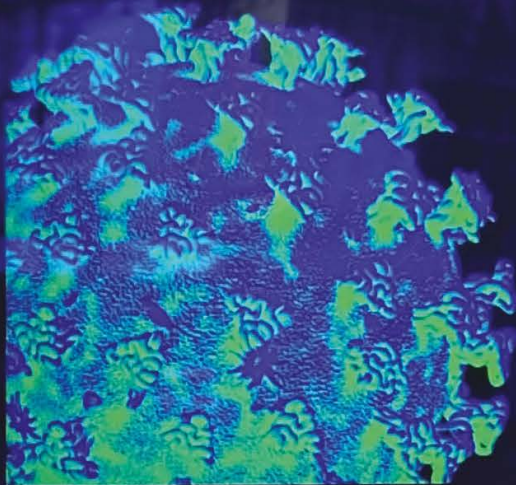
CORONAVIRUS STAY AT HOME SAVE LIVES



Anyone can spread Coronavirus.

The only reasons to leave home are:

- ✓ To shop for basic necessities or pick up medicine
- ✓ To travel to work when you absolutely cannot work from home
- ✓ To exercise once a day, alone or with members of your household
- ✗ Do not meet others, even friends or *family*



CORONAVIRUS

**STAY HOME
PROTECT
THE NHS
SAVE LIVES**

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SECTION 7: APPENDICES

APPENDIX 1:

LC006 CASE STUDY

Participant LC006 is a 64-year-old lady, one of three siblings. She was born in West Belfast. She is of short stature and of low educational attainment. PX left school at 15 years old and worked as a seamstress in various factories. She was married in her late twenties. She said that her husband was often physically abusive towards her. She had one son who subsequently availed of drugs at an early age.

LC006 did not start drinking until her 40's and claims that this was a coping strategy to try and help her cope with her son's wayward behaviour as a teenager. Before long, alcohol took over her life and she was then separated from marriage.

She moved from one hostel to another and ended up living on the streets and often begged for money. She also became involved in crime and was considered a 'revolving' door prisoner with around 220 convictions which involved theft, assault, drunken disorderly and was in and out of HMP Hydebank.

Due to the chaotic nature of her life, PX soon became estranged from her siblings and they did not want any further involvement with her.

"Oh god you are not going to like this, it's definitely not me but the drink was involved, I was in jail, before coming here, I was in for around 2 months and it wasn't my first time. I was just out of control with drink in me.... Once the drink kicked in I gave off and I have lost a lot of friends through it just being daft. In here is recovery time, so 9 months without one drink, I haven't even thought about one.....I got a serious injury out of it (fighting due to excessive drinking).. I got a broken shoulder out of fighting, not fighting but an argument with this girl and she was a lot younger than me and she hurt me..." (LC006 6 months).

PX from West Belfast and was well known in the area. Some locals often gave her alcohol and then taunted her just to get a reaction from her for their own entertainment. People would have sworn at her to make her angry and then she would retaliate both verbally and physically.

"I actually got caught up in (social media) someone, filmed me, it went viral, I was totally in horror with what I was doing but the drink was in. I couldn't believe it and I ended up in prison and everything, not good..... I have friends who went through it too. My friend has a daughter

who is severely disabled, and I went into her house one night with drink in my system and she said (XXX) you can't be doing that, especially the way the wee girl is in case I took a trip and fell on top of her or something. It wasn't good.... I got my son to phone her a couple of times, she is doing ok" (LC006).

After some negotiating, PX was referred to Leonard Cheshire (ARBI) for rehabilitation whilst she was in Hydebank.

"When I was in jail I was diagnosed and we had a talk and they were saying about me coming here. I thought that's ok as long as I wasn't going out to nothing and having to do it all myself, it was all set up for me, the room was all ready for me. It just happened from there then (LC006).

LC006 presented with significant memory deficit not in keeping with her age. She had self-care neglect issues and refused to wash her hair and change her clothes. She also presented with a significant tremor at rest.

At presentation she would not get washed or changed for anyone, the client appeared as shy and modest. The Clinical Lead for LC unit at the time, adopted a person-centred approach from a planning point of view and was able to build rapport and trust with the client. She was soon able to get LC006 to agree to get into the bath to get washed and the CL agreed to turn her back and face the other way when client was undressing. The CL adopting this person-centred approach broke down the barriers with the client as she realised that she had some control in the process.

"I was down, where do you call that, I forget the name of the place. A recovery place in Newry, you wouldn't have been able to do half the things in there.... because you felt as if you were, how do you explain? I lasted 3 days, that's all I lasted and my son said please mum. I just said, you are not here, I am. Whereas in here, I feel much more, normal..... Nobody judges you in here, that's one thing I will say, not one person, staff member, manager or anyone. You can laugh and joke with them and I just feel comfortable, and that for me, has made all the difference..." (LC006).

"I felt a bit strange at the start because I was counting on going into my own place, so it was a wee bit strange coming into other people's company but I just got on with everybody..... I just take them as they come. There is no point in me thinking I'm better than anybody else

or I'm too good for this place, that's not the case. I get some craic going, talking funny and all and saying silly things to the staff The fella that's helping me out now, cleaning my room, he's an eejit..... He's very tall..... I call him the Eiffel Tower.... I said to him one day you remind me of the Eiffel Tower and he says oh thank you, took it all in good fun" (LC006).

The rehabilitation unit also put in place a rota to help the client with her laundry and this proved to be very successful.

During her stay of over 2 years in the unit there was not one incident of antisocial behaviour. She was well liked and respected by the other residents and her history remained confidential throughout her stay at LC.

"People do make something out of something about my size, and nobody in here has ever said anything to me about my size and I find that lovely. The guy that's with me now, he takes the mickey out of me but he doesn't mean it.... I give him stick and he gives me stick back" (LC006)

"I just take them as they come. There is no point in me thinking I'm better than anybody else or I'm too good for this place, that's not the case. I get some craic going, talking funny and all and saying silly things...."(LC006)

During her time in the unit her memory slowly started to improve. She also progressed from not wanting to eat in front of anyone to coming down to the dining room and eating her meals with the other residents. She also engaged with other activities within the unit, for example, she did Mindfulness on a daily basis and very much enjoyed it.

"I get on with people and then we do chores. I'm the cleaner, the duster of the day. do the likes of in here, the tables, polish, mostly polishing but it gets the day in... Because you can become, some people in here stay in their rooms and don't come here for their lunch or outside for a smoke or anything like that.... There'd maybe be 4 or 5 who would eat their meals in their rooms, Don't get me wrong I have done it too instead of coming down here if I'm watching TV or something. I'm into the game shows, I've never watched The Chase and I'm really into it now" (LC006).

She did not like to venture out of the unit however. It was thought by the staff that perhaps going outside into the 'real world' might be a trigger for her, especially without alcohol.

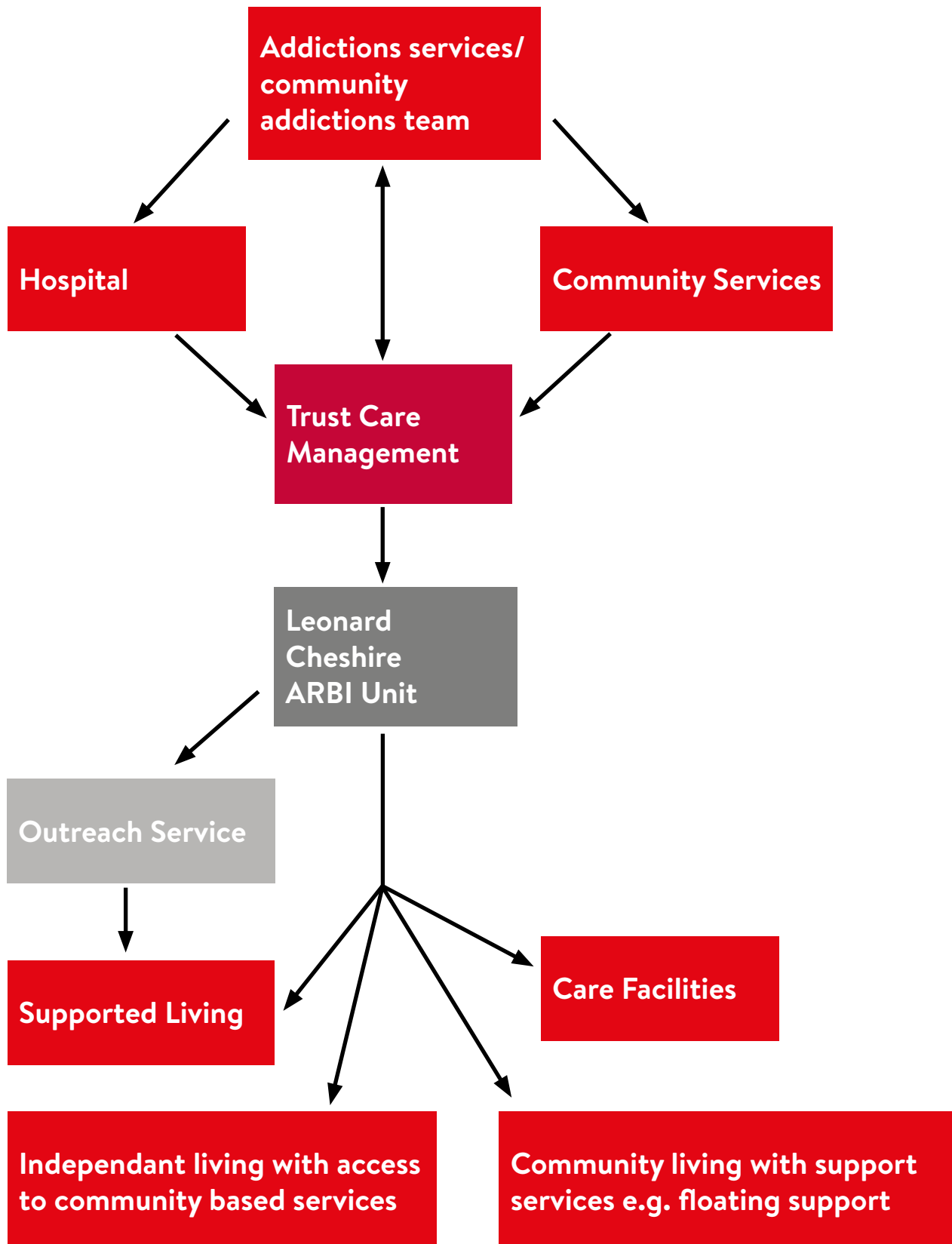
In terms of washing and dressing herself, she required some assistance doing this due to her tremor. Upon discharge, LC006 was placed in (XXXXX) nursing home and then (Nursing Home).

Both her brother and sister were informed of her discharge and new placement but were not interested in engaging, however, her son has been visiting her and has shown her photos of her grandson. This relationship with her son has only been salvaged because LC006 has now been abstinent for over 2 years and has not been involved in any adverse incidents, in fact her demeanour has been very pleasant and accommodating. LC006 has had the opportunity through LC to find safety, stability, kindness and security. This has enabled her to build trusting relationships again and live in a stable environment. As a consequence, she has been able to stay away from alcohol and the Criminal Justice System and turn her life around.

"I definitely have improved since I came here, people have said when I first came in here I was a bit shy and kept myself to myself, didn't really talk too much and kept my head down, just got on with it. The staff that are with me now doing my room, big tall guy, he's lovely and you can joke with him and he would joke back. All the other staff are the same too.... I wasn't looking after myself [before coming in here], I wasn't into too much cleaning then and I wasn't into opening up with other people but I had no other choice, that's life as it comes.." (LC006).

"I'm glad I'm not drinking anymore because it was wearing me out....have been off it now for just over a year and before that I was drinking most days..... It's a big difference now but at the end of the day it was my health and other things, physically and mentally were suffering..... I'm feeling a lot better now, I'm eating a lot better and doing the odd bit of exercise..... they do all sorts in here.... exercises or classes, quizzes as well, I love them... everybody goes to the one thing and then the staff carry out the quiz.... I'm back to my old self. I like the odd joke and I like to be happy" (LC006).

APPENDIX 2: CARE PATHWAY FOR PEOPLE WITH ARBI



APPENDIX 3: THERAPEUTIC PHASES OF REHABILITATION IN ARBI

Table 14. Number of service users interviewed at each timepoint.

Therapeutic phases of rehabilitation in ARBI.		
Wilson. et. al. (2012) The Psycho-Social Rehabilitation of Patients with Alcohol Related Brain Injury (ARBI) in the Community		
Phase	Characterisation	Duration
1. Stabilisation	Acute withdrawal, management of encephalopathy, thiamine supplementation, physical stabilisation. Usually carried out in acute medical wards	Variable; dependent upon physical health
2. Psycho-Social Assessment	Evidence of fairly rapid improvement in cognitive and behavioural profile. Period of ongoing assessment in a therapeutic environment. Introduction of early routine, structure, and support. Regularisation of sleep, appropriate nutritional maintenance, and mood stabilisation. Development of therapeutic relationships. Early engagement with family and carers	May last up to three months. Duration may be increased when complicated by other organic or psychiatric conditions
3. Therapeutic Rehabilitation	Period of more gradual improvement in cognitive and behavioural skills. Milieu based approach. Rehabilitation in an ecologically relevant, adaptable environment. Focus on cognitive, emotional, social behavioural and functional skills development. Development of social relationships and therapeutic relationships.	May last up to three years. Can be complicated by co-morbid physical and mental illnesses.
4. Adaptive Rehabilitation	Rate of cognitive and behavioural improvement has slowed or ceased; social and physical environment is adapted to optimise independence by compensating for residual cognitive and functional deficits	Duration may vary dependent on personal circumstances and access to facilities
5. Social Integration and Relapse Prevention	Building new social relationships, structured routines, and alcohol relapse prevention	Long term follow-up required.

APPENDIX 4: MODEL FOR ARBI UNIT

