



# Evaluation of Rainbow Lodge

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## EXECUTIVE SUMMARY

Rainbow Lodge (which has been operational in Ballymena since June, 2003), is a specialist children's home for children and young people with learning disability and challenging behaviour. It is managed by Challenge which is a voluntary organisation specializing in this area of work.

## Aims and Purposes of Study

This evaluation is being undertaken, at the request of the Northern Health and Social Services Board (NHSSB) to:

- evaluate the operation of the unit,
- identify the needs of children and young people who receive a service from Rainbow Lodge and involve them within the evaluation,
- assess the degree of satisfaction of children, families and professionals who previously and currently use the service and inform multi-disciplinary practice and strategic planning within NHSSB.

## Main Findings

- The Unit provides a user-friendly service which is highly rated by both professionals and parents/guardians.

- The majority of parents/guardians believed their child had benefited from care in the unit
- Unit staff were praised for their openness, helpfulness and for the 'excellent' relationships which they have developed with the children.
- Both parents/guardians and professionals agreed that the children were subject to "planned care through ongoing assessment and regular reviews", however there were some concerns regarding the absence of an assessment bed and the need for transition planning.
- In terms of service impact, children who were in receipt of permanent care benefited most.
- There is a recurring pattern amongst the children receiving permanent care placements. They showed most improvement in all areas. The least improvement overall was amongst the children receiving respite care.
- Although the policy aim has been to reduce the numbers of children accommodated in hospitals, there is still a need for some hospital provision from time to time for those children with extremely complex health needs.

- Children in Causeway Trust are not able to access any of the range of specialist family support services available to children with similar needs in Homefirst.
- Formalised communication networks between other community service providers are key to providing a coherent multi-disciplinary service.

### **Recommendations**

- See Section 4 pg. 37.

## 1) INTRODUCTION

Rainbow Lodge, is a specialist children's home for children and young people with learning disability and challenging behaviour. Situated at Hugomont Drive in Ballymena, it is managed by the voluntary organisation Challenge and has been operational since June, 2003. This evaluation is being undertaken, at the request of the NHSSB.

**Aim: To assess the effectiveness of the services provided by Rainbow Lodge,**

### **Objectives:**

1. To evaluate the operation of the unit by obtaining information from parents/guardians, carers and professionals about their understanding, experience and expectations of the service.
2. To involve the children and young people who currently receive a service from Rainbow Lodge in the evaluation and identify their needs.

3. To assess the degree of satisfaction of children, families and professionals using the service.
4. To inform multi-disciplinary practice and strategic planning within NHSSB by circulating the research findings.

Whilst there is a clear connection between the policy and the legal context within which Rainbow Lodge was developed, we will consider them separately.

### **1.1 Standard Function and Purpose of the Unit**

In 2000, the NHSSB required the unit to provide a range of specialist services through residential care, day-care and outreach.

There is a clear requirement in the service specification that the unit will provide:

- Specialist assessment and treatment of behavioural difficulties within the residential provision;
- Clinical and therapeutic intervention programmes.

The unit's design is modular to facilitate the separation of

provision for children requiring 4 permanent or shared care beds and 4 respite beds.

At the end of its first 18 months in operation, the unit is providing permanent care for 6 children, shared care for 2 children with the remaining 19 children using less than 2 respite beds.

Referrals for respite represent 70% of the total but amounts to less than 25% of the utilization of beds.

Causeway Trust presently have no provision for weekend respite.

The unit can accommodate 8 children at any one time and overnight stays are encouraged to optimize the use of beds. There are 2 children presently using the day care facility only.

## **1.2 The Legal Context in N Ireland**

The development of services for children with disability is underpinned by the Children (NI) Order, 1995.

Having identified children with a disability as “Children in

Need” (Article 17) of the Order enshrined their rights alongside those of all children, requiring them to be considered to be “children first”. In their provision of services, authorities must provide services which will support families to continue caring for the child who has a disability within their family home.

The basis for this new approach lies in the Education and Libraries (NI) Order 1986, which focused on improving educational experiences for children with special needs. In bringing together social and educational needs for the first time the 1986 Order placed children with disabilities on the agenda for health and social services.

The requirement for statutory bodies to be proactive in developing policies and services promoting inclusion and equality is incorporated in legislation which is not just specific to children (e.g. Article 75 of the NI Act, 1998)

The concept of inclusion through citizenship is further

defined within the Human Rights Act, implemented in Northern Ireland in October, 2000. The appointment of the Children's Commissioner for Northern Ireland in 2003 further underlines the significance of the human rights dimension which must be reflected in the provision of services for children.

### 1.3 The Policy Context in N Ireland

During the 1990's there was a growing awareness and concern about the variety of residential environments (including hospital settings) where children who had disabilities were living.

This issue was partly addressed in the 1995 DHSS publication of The Review of Policy for People with a Learning Disability. The review expressed concern about the increase in both the admission rates of young people to hospital and in the number who were staying in hospital for longer periods.

The Review recommended that the needs of these young people should, in the future, be

met through specialist support in the community.

The Regional Strategy for Health and Social Well-being 1997-2002 further developed this recommendation by identifying specific targets for children with a learning disability.

“As an integral feature of the comprehensive services, specialist provision should be linked to community-based care and treatment which should reduce the number of children (admitted to specialist hospitals), other than in exceptional cases, to zero by 2002”.

In response to this requirement the Board commissioned research by the University of Ulster, examining the needs of children using a specialist hospital service and a consideration of how these needs might be addressed by community-based alternatives.

The final report “Responding to the Challenges – Consideration of Service Options for Children with

Learning Disabilities, 1998” recommended that the Board should commission a specialist 8-bed, community-based residential unit to meet the assessment, treatment and residential care needs of children with a learning disability and severely challenging behaviour.

The Board responded to the University of Ulster Research in its February 2000 document “Service Specification: Specialist Children’s Unit for Children with a Learning Disability and Severely Challenging Behaviour” which outlined its intention to commission a specialist facility for this group of children.

The function of the facility was to “provide a base for the co-ordination, and/or delivery of as many as possible of the specialist services currently provided at Muckamore Abbey.”

In addition, the Board in its 1998-2002 strategy, ‘Promoting Ability: A Strategy for the Development of Care

for People with a Learning Disability’, acknowledged the continuing need for a small number of children to access specialist hospital assessment and treatment.

In June 2003 the voluntary organisation Challenge was successful in its tender to develop a purpose-built, 8-bed unit, now known as Rainbow Lodge.

In continuing to commission one bed in Conicar (the children’s ward in Muckamore Abbey) from North & West Belfast Health & Social Services Trust (North & West Belfast Trust), the NHSSB recognises the continuing need for a very small number of children and young people who will need to access a hospital bed for assessment, and treatment purposes.

In February 2004 North & West Belfast Trust published “Development of a Community-Based Specialist Assessment and Treatment Service for Children and Young People with a Learning Disability”.

Whilst the detail of this proposed development is not yet known, the Board wishes to continue commissioning one

bed within the regional assessment and treatment unit to support its community based service provision.

From a broader perspective the current DHSS&PS regional inspection of services for children with disabilities will also inform the development of future services.

#### **1.4 Family Support Services within the NHSSB Area**

The statutory requirement for authorities to provide family support services to children in need (of which children with disabilities are part) derives from Article 18 of the Children Order.

In 2003, the government's Green Paper "Every Child Matters" established 5 desired outcomes for children:

- Being healthy
- Staying safe
- Enjoying and achieving
- Making a positive contribution
- Economic well-being

Within the NHSSB, a range of family support services for children with disabilities have been developed, many in

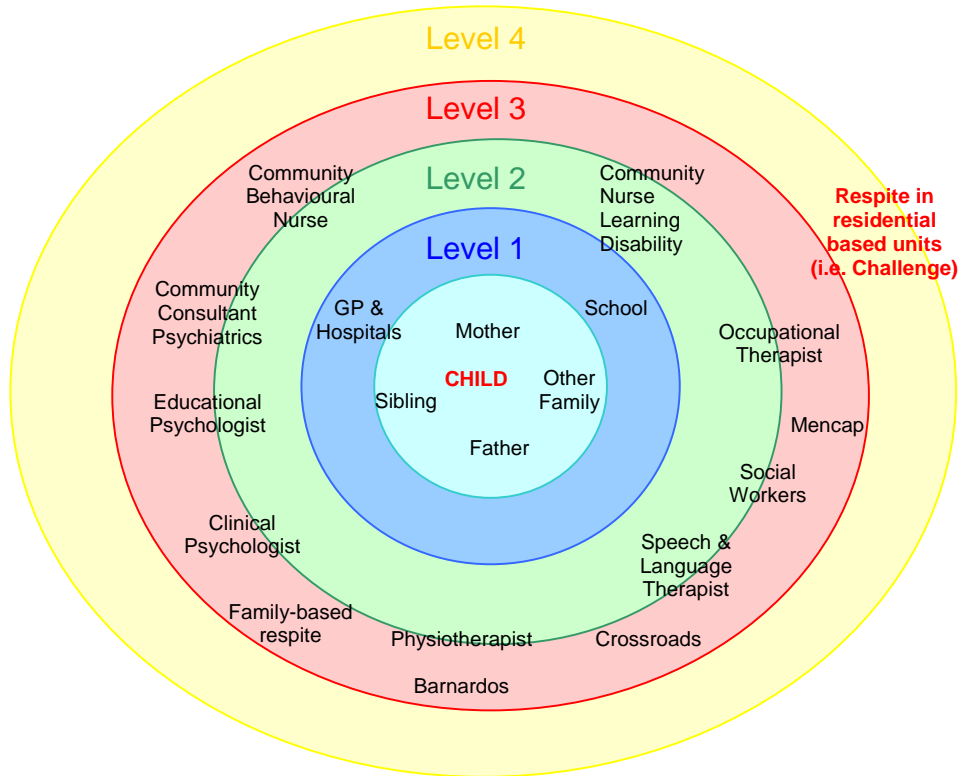
partnership with voluntary organisations.

The provision of appropriate services and support is informed by a needs assessment for each child and their family. Using the Assessment Framework, a variety of professional disciplines as well as the family contributes to this assessment.

The publication "Every Child Matters" highlights the challenge for Trusts and Boards staff and managers: "How best to support the particular needs of families with disabled children, who require flexible services responsive to their particular circumstances and needs".

Children with disabilities and their families may be in contact with a highly complex network of professionals and organisations as presented in Fig. 1.

**FIG. 1: RAINBOW LODGE'S PLACE AMONGST LOCAL SUPPORT SERVICES FOR CHILDREN**



*Adaptation of Hardiker (1991) and Bronfrenbrenner (1996) Models*

## 2) METHODOLOGY

This study investigated the range of services and therapies being offered to and used by young people within and outside of the unit.

### 2.1 Sample

The sampling frame for all groups was identified through file analysis and discussions with the unit manager.

**Table 1: Groups sampled by response rate**

GROUPS	SAMPLE SIZE	RESPONSE RATE
<b>1) PROFESSIONALS</b> (I.E. Working externally but in partnership with Rainbow Lodge)	<b>56</b>	<b>26 (56%)</b>
Social Workers	10	9 (90%)
Medical	4	3 (75%)
Managerial	9	7 (78%)
Education	7	2 (29%)
Rainbow Lodge Staff	24	6 (25%)
Community Nurses	2	0 (0%)
<b>2) CARE FACILITATORS</b> (I.E. Working internally with children placed in Rainbow Lodge)	<b>27</b>	<b>12 (42%)</b>
	<b>9</b>	<b>2 (22%)</b>
<b>3) PARENTS</b>		
<b>4) PAST USERS</b>		

### 2.2 Research Instruments

Questionnaires were designed, piloted and administered to investigate the units' adherence to the service specification and to examine whether the unit is meeting the needs of its service users.

All postal questionnaires were self-administered and were accompanied by a letter of explanation from the Board (see Appendices 1-4). They were designed to elicit both quantitative and qualitative information using closed and open-ended questions.

As a result of responses from carers, senior managers were contacted in both Trust areas to elicit specific information concerning the professional contact between allied health professionals and the families.

The research remit required an investigation of the effect of Rainbow Lodge on other service providers. Comments and service statistics were sought and integrated into the findings section.

## 2.3 Analysis

Qualitative analysis of the paper-based questionnaires was undertaken in order to produce thematic outcomes.

Qualitative comments from the senior managers and information from service records was also integrated into the thematic results.

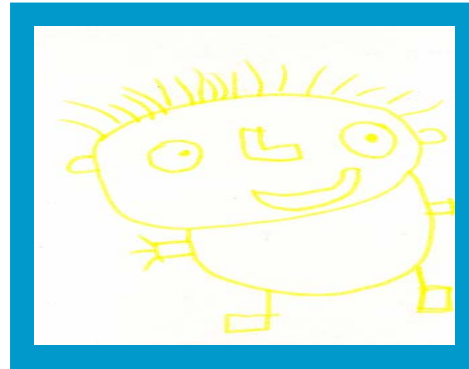
## 3) FINDINGS

### 3.1 About the Children

In order to meet the aim and objectives of the evaluation, it was necessary to identify all of the children who had used Rainbow Lodge since its opening. Data in relation to the children who presently use Rainbow Lodge was gained through a review of case files with the co-operation of managers and staff of the unit. In addition to identifying the children who currently use the service, the children who previously used the service but no longer do so were also identified.

The purpose of this service utilisation was to determine whether the home is operating in accordance with the service specification and its statement of purpose and function.

The unit shall provide:  
*“A range of respite, shared care and longer term care and assessment services for children and young people with a learning disability and severely challenging behaviour who may also have a physical disability and complex health needs”*



#### 3.1(i) Past Users

Rainbow Lodge was opened in 2003, and the first child was admitted on the 22 June. Prior to 31 August 2003 there were 28 children using the services, 6 were females (21%) and 22 were male (79%).

During this period 8 children withdrew from the services. One child withdrew because the distance traveled was too great for the amount of service allocation. One child moved to facilitate appropriate Adult Service provision in the future. Of the remaining 6 children, 2 chose to remain with their existing service at Cherry Lodge and a further 2 left because they were dissatisfied with the service. 25% (n=2) of the parents/guardians whose children were withdrawn from the service found the service unsuitable for the children's needs.

### 3.1(ii) Current Users

27 children were using services within Rainbow Lodge Children's Home on the 31 of July 2004. Of these children 3 are female (11%) and 24 are male (89%). The ages of the children range from 6 to 18 years with the mean age for females being 12 years and 12.2 years for males.

The services provided vary according to the needs of the children and their families.

At present there are nineteen children using respite facilities (i.e. 17 using daytime services and 2 using overnight services), two using shared care and six who have permanent residence at Rainbow Lodge.

All six of the children with permanent residence are above the age of 14 years and will soon need alternative provision.

The children accessing services at Rainbow Lodge come from across the Board's area. 70% (19) live within Homefirst Community Trust area and 30% (8) come from Causeway.

It is noteworthy that there are some geographical areas within the Board area from which very few children access the service. Children from these areas have no accessible residential facility.

### 3.1(iii) Learning Disability

The **basic criterion for referral** to the unit was that children would have a:

**severe learning disability is** "Learning disability is a lifelong irreversible impairment of intelligence which significantly affects social functioning. However, each person's individual learning ability, skills and quality of life can be improved". (Murray and Heatherington, 1998)

An individual with "Severe Learning Disability" has an I.Q. of less than 55.

Of the 27 children using Rainbow Lodge, 26 were classified as having a severe learning disability and 1 as having a moderate learning disability.

In addition, a number of more specific diagnostic categories were identified including 16 children having Autism, 6 children were diagnosed as having ADHD. Furthermore, 3 children were identified as having Global Developmental Delay, 1 child as having Downs Syndrome and 1 as having Tuberous Sclerosis.

### 3.1(iv) Challenging Behaviour

The **second criterion** for referral to the unit was that children would be exhibiting:

**severely challenging behaviour** i.e. “behaviour of such an intensity, frequency or duration that the physical safety of the persons or others is placed in serious jeopardy, or behaviour that is likely to seriously limit access to the use of ordinary facilities” (Emerson, 1987).

All of the children using Rainbow Lodge display a range of challenging behaviours within the unit. These include physical and verbal outbursts, and throwing objects. The most prevalent behaviours are physical outbursts displayed by 79% (n=21) of the children.

The risk of wandering if given the opportunity is an issue for 60% (n=16) and 56% (n=13) direct physical outbursts towards him or herself.

### 3.1(v) Complex Care Needs

A number of children have also been identified as having a range of disabilities and an associated range of health care needs.

Of the children using the service, 14 have 2 or more disabilities, 5 children have 3 or more disabilities and 1 child has 4 disabilities.

Nearly a quarter (22%, n=6) of the children require the use of forms of walking aid for mobility with 3 of those children having partial reliance on a wheelchair.

48% (n=14) can use verbal communication, with the remainder using symbols or gestures. 4% (n=1) have a profound hearing loss.

In terms of personal care 63% (n=17) require assistance with both dressing and bathing.

While 8% (n=2) have independent skills in both these areas. 55% (n=15) of the children are not continent and 37% (n=10) require assistance with eating.

None of the children require assistive technology for their continued well-being and none have life-limiting conditions.

The children have a range of combined needs which are complex in their nature, requiring specialist support from a range of professionals.

### 3.1(vi) Accommodation Needs

After intellectual and behavioural criteria are met, there are 4 further reasons for referral. These include the need for respite, shared care, permanent residence and finally assessment.

According to records, 19 children have currently been referred to the unit for respite, 6 for permanent residence and 2 for shared care services.

Of the children having permanent residence, 4 are subject to care orders (i.e. 2 children from Causeway Trust and 2 from Homefirst Trust) which means that parental responsibility lies with the Trust rather than the parent.



## 3.2 RESPONDENT VIEWS

### 3.2(i) Professionals' Views

Almost all of the professionals felt they had an understanding of the role and function of the unit when it opened in June, 2003. They stated that this was to provide respite care, shared care and residential care to children with a severe learning disability and challenging behaviour.

A third of professionals identified a secondary function of the unit to provide treatment and outreach services.

Since using the services of Rainbow Lodge 50% (n=13) of professionals now feel their expectation of the role has changed.

The professionals mostly identified a lower than expected level of respite services and the lack of outreach provision. The level of availability of assessment and the lack of behaviour intervention programmes were also identified.

Just over half of the professionals felt their expectations had been fulfilled since using Rainbow Lodge.

The explanations for their unmet expectations are similar to those explained above.

In terms of the original aims and objectives of the facility, the majority of professionals agree that it provides a range of services including respite, shared care and long-term care.

Professionals were less decisive in their views regarding the extent to which the unit provided an assessment service.

Whilst half agreed that it did provide the service, a fifth disagreed and a quarter was undecided. Those who felt the unit did not provide the assessment service gave explanations which included discrepancies in the criterion for admission, the 'inflexibility' of assessment services due to the high demand for residential care and the "lack of psychological input" into behaviour modification programmes.

The current absence of an assessment bed was highlighted by professionals.

The loss of this resource is particularly problematic for children who require assessment out of their home and also for children requiring emergency placement (as this bed was additionally used for this purpose).

From the professionals' perspective, the most useful/effective elements of the overall service in order of priority are the residential care, shared care and respite care.

Of the respondents who stated that respite care was a useful service, two-thirds emphasized that the level of provision was not what they initially expected.

An additional aspect valued by professionals was the work done by the unit to reintegrate children into school. This finding mirrored the care facilitators' responses (see section 4.2(ii) pg. 20).

Very few professionals stated that behaviour management programmes were a useful aspect of the overall service.

Additional issues of concern included, lack of behaviour management, psychology input, lack of consistency in managing a child's behaviour between the school and the unit and the lack of outreach. These responses indicate that professionals believe the original range of provision identified within the service specification is required by the children currently using the service.

The increasing use of the unit to provide permanent care for children has clearly impacted on the availability of respite care beds and is a recurring theme of concern amongst professionals.

### **3.2(ii) Parents/Guardians Views**

Of the 12 parents/guardians who replied a third stated they had no children other than the child in Rainbow Lodge.

All of the children who use Rainbow Lodge have access to a wide range of services.

Responses mostly suggest the use of social workers, teachers and GP's, with the least used services being Community Nurses for Learning Disability and Educational Psychologists.

According to the responses received, the community behaviour nurse service is not used. It is important to note that this latter service was developed as part of the continuum of community based family support services to assist children with learning disability and severe challenging behaviours.

There is a wide variation in the number of interventions (i.e. therapies, behaviour programmes etc.) received, with some children receiving no interventions and others receiving up to 9 (see table 2 page 19).



The range of disabilities of each child which led to the need for using Rainbow Lodge was a recurrent theme in the parents/guardians responses. They emphasized the demanding nature of their children's needs and highlighted the need for constant supervision.

One quarter of parents and guardians suggested that the opportunity to "recharge their batteries" and spend more time with other family members was why their child commenced using the services provided by the unit. Additional factors identified included stress, lack of other support networks, and disruption of previous placement.

Parents and guardians also identified potential benefits for the child in using the unit. They expected that the quality of the facilities offered and the 1 to 1 supervision proposed would have a positive impact on all aspects of their child's development with one third anticipating their child would benefit socially and emotionally from the service.

Parents/guardians believed that Rainbow Lodge would provide their child with all the "care and attention" required.

### **3.3 IMPACT OF THE SERVICE**

#### **3.3(i) Parents/Guardians Views**

##### ***Services Received in Rainbow Lodge***

The most valued element of the service was the potential to relieve family stress. The provision of respite, shared-care and permanent accommodation, along with the potential for new experiences for the child, was also valued. These elements broadly reflect the reasons given by families who commenced using the service.

Behaviour modification and complementary therapies were reported as least valuable by parents/guardians. The lack of value attributed to behaviour modification may reflect its very recent introduction, rather than ineffective programmes being implemented.

When asked for additional comments, some parents/guardians stated their children were happy and contented since using the service, that the unit was a “great service” with benefits for the family as a whole.

Over two thirds commented on the qualities of the unit’s “excellent” staff stressing their approachability and the relationships which they have with the children.



##### ***Services Accessed Outside of Rainbow Lodge***

Some parents/guardians stated that since their child had commenced in the unit they had received additional services from professionals who work outside of Rainbow Lodge. They mentioned weekly respite from a support worker, services from a consultant psychiatrist and referral to an outpatient’s clinic.

Practice has developed so that one community consultant psychiatrist comes to the unit with parents consent. This practice is less disruptive than a hospital visit and facilitates improved communication in relation to the child’s care.

There are notable differences in the number of services being accessed by individual children and responses indicate that the use of additional services outside of Rainbow Lodge has not increased.

### ***Physical Attainment***

Changes in children's physical ability were mixed with one positive and one negative change (i.e. due to physical health of the child rather than as an effect of the service).

### ***Behaviour***

Nearly three-quarters of parents /guardians who responded stated that there had been behavioural changes in their child, including a decrease in the intensity and frequency of self-harm episodes and improvements in all aspects of behaviour.

A third of parents/guardians stated that using the unit had not produced any change in their child. The children with reported deterioration in overall behaviour included increased intensity and frequency of incidents of self-harm.

### ***Social and Emotional Attainment***

Two thirds reported improvements in the child's social and emotional ability, particularly noting improved eye contact and an increased interest in peer interaction and conversations.

### ***Personal Care***

Parents/guardians did not specifically comment on this area.

### ***Educational Attainment***

Of the respondents who identified changes in their child, three had observed general changes. A number of children's behaviour in school has improved, with one child receiving the prize for the most improved pupil of the year.

Not all respondents felt there was an improvement in their child's educational attainment since using Rainbow Lodge.

The majority of parents/guardians believed their child had benefited from care in the unit, however one felt they had not due to the level of respite on offer.

According to parents/ guardians, the greatest overall improvements for children attending Rainbow Lodge was in social and emotional attainment. The most noted social skills and improved ability to use community resources.

In terms of meeting their initial expectations of the unit the majority said these had been fulfilled. Some stated that their unfulfilled expectations were due to the level of respite provision being less than expected.

### **3.3 (ii) Care Facilitators' Views**

#### ***Services Received in Rainbow Lodge***

The majority of children accessing Rainbow Lodge are participating in specific intervention programmes (i.e. all of the children in shared care and 80% of children receiving either respite or permanent care.

According to the care facilitators 5 children are not using any specific intervention programme.

There is evidence of the use of a range of techniques and approaches in Rainbow Lodge (e.g. the use of ABC charts and distraction and diversion techniques) with an additional overlay of specialist techniques (e.g. Communication methods such as Makaton, Picture Cards and the use of TEACCH). The type of techniques used can be seen in the following table.

**Table 2: Interventions Used in Unit**

Placement category	Proportion	Type of intervention	No of children
<b>Permanent residence (n=6)</b>	5 (83%)	<ul style="list-style-type: none"> <li>• Daily living training and independent living skills</li> <li>• TEACCH (<i>Treatment and Education of Autistic and Related Communication Handicapped Children</i>)</li> <li>• CALM</li> <li>• Behaviour modification programme</li> </ul>	3 2 2 1
<b>Shared care (n=2)</b>	2 (100%)	<ul style="list-style-type: none"> <li>• ABC chart (<i>Antecedent, behaviour and consequence</i>)</li> <li>• Daily living training and independent living skills</li> </ul>	1 1
<b>Respite (n=19)</b>	15 (79%)	<ul style="list-style-type: none"> <li>• CALM (<i>Crisis and Aggression Limitation Management</i>)</li> <li>• Daily living training and independent living skills</li> <li>• Distraction &amp; Diversion Techniques</li> <li>• Picture Card Communication</li> <li>• Specialised Social Activity and Structure (ASD)</li> <li>• C &amp; R (Care and responsibility)</li> <li>• Makaton/Sign Language</li> </ul>	5 1 3 3 1 1 1

The limited amount of behaviour intervention and therapeutic programmes highlighted mirrored responses from professionals.

One possible explanation is that the psychology service was introduced very recently in to the unit and knowledge of the service may be low.

### **Physical Attainment**

The greatest improvement for two thirds of the children in **permanent residence** was decreased reliance on support when walking, with 1 of these children now able to walk without staff support. For children in **respite care**, no improvements were made in the children's physical ability (i.e. mobility, walking independently, dependence on aids). Within the **shared care** category, a quarter of care facilitators identified changes in children's physical ability, 1 being positive change and the other negative.

### **Behaviour**

Within the **permanent residence** category no children deteriorated in any of their behaviours. There were reported improvements in some areas including physical outbursts, self harm and night disturbance.

Within the **respite category** the most improvement was reported in the reduction of physical outbursts with approximately half of the children showing decreased levels of disturbance during the night. The behavioural aspects which showed least variation were disturbing noises, self-harm and verbal outbursts. Similarly children in **shared care**, improvement were shown in the majority of problem behaviours. There were noted deteriorations in physical outbursts and self harm for this small group of children.

### **Social & Emotional Attainment**

The greatest social and emotional improvements, for children in **permanent residence** were in communication, interaction with staff and use of community resources with all children showing improvements. Interaction with peers remained unchanged for a third of the children.

Within **respite care** the greatest area of improvement was in the area of communication with two thirds of children showing more regular interaction with staff.

Seven children showed improved peer interaction while only one had a reduced ability to use community resources.

Within the **shared care** category all children improved in the areas of communication and peer interaction. Noticeably in this category there was no variation in the children's ability to use community resources.

There is a recurring pattern amongst the children receiving permanent care placements. These children experienced most attainment in all areas. The least attainment overall was amongst the children receiving respite care.



### **Personal Care Attainment**

The greatest improvement for the children in **permanent residence** was in the area of dressing and bathing, with all children requiring a lower level of assistance and the majority having improved eating skills. Variation was minimal in continence control. Within the **respite category** the areas of greatest improvement were in eating skills with nearly half showing increased ability to use a spoon, levels of prompting the child to eat or assistance required. This category also reported increased level of continence and less assistance when dressing and bathing. The greatest improvements in the **shared care** category were in self-care skills with both children showing progress in those areas. Continence ability remained unchanged. Across the placement types the most attainment in the unit has been made in the area of personal care, i.e. dressing and bathing and eating skills. Continence tended to show less variation.

### **Educational Attainment**

The children receiving **permanent care** showed the greatest improvement of all in school with care facilitators reporting attitudinal improvements in three out of four children. Two children increased the amount of time spent in school each week one of whom was re-allocated a full-time placement in school. It is important to emphasise that two children received school awards for the “most improved pupil”

One child in **respite care** showed improvements in the amount of time spent in school and another exhibited improvement in behaviour while at school. However, some children’s educational performance did deteriorate with one child spending less time in school. Additionally the attitude to school attendance of two children had deteriorated since using the services at Rainbow Lodge. Within the **shared care** category educational attainment tended to remain unchanged, however the behaviour of 1 of 2 children had deteriorated in school.

The same recurring pattern exists for in all areas of attainment where children in permanent care have shown the most consistent improvements. This confirms the good quality of day to day care being provided by the unit staff.

The children who demonstrate least variation are those receiving shared care and respite care.

There is evidence of deterioration in some facets (e.g. school behaviours, self-harm, physical outbursts). Continence showed least variation alongside some other behaviours such as self-harm and physical outbursts which are more complex behaviours to change.

There is unlikely to be a single explanation for the variation in impact between the types of placement which children experience but a number of factors may be of relevance:

1. The restricted level of respite care available is a concern for both professionals and parents /guardians. Children who attend for respite care have less contact with unit staff and therefore less opportunity to be worked with on a regular and ongoing basis.
2. Rainbow Lodge does not provide an outreach service. In terms of access to outreach services, children from this unit have only been able to access community nurses for learning disability within the adult services framework (in Homefirst Trust). In addition, community behaviour nurses are only available within Homefirst Trust and not Causeway.
3. Parents/guardians report that their children have contact with Speech and Language Therapists, Occupational Therapists and Physiotherapists. In practice, Rainbow Lodge does not record all of the professionals involved with the children. In the absence of a protocol to record such information, the ability to network on issues of importance and concern is impaired.
4. The lack of psychology input at Rainbow Lodge until October 2004 was also a concern, especially in terms of therapeutic and behaviour management programmes. A psychology associate now spends 3 days per week on work related to the unit.
5. Working with children who have severe learning disability and severe challenging behaviour requires specialist skills amongst staff and this area will be further addressed later in the document.

### **3.3(iii) Additional Indicators of Service Impact**

The impact of the service was also looked at in terms of its effect on services such as 'Conicar' (i.e. Children's Ward in Muckamore Abbey Hospital, Antrim) and other community family-support services.

Additional information was obtained from the information and analysis unit at NHSSB where the numbers of respite cases at Conicar were recorded between June 2002 and December 2004. Comments were sought from board-wide children's disability services managers.

### **Impact on Conicar**

Conicar continues to be used for both respite care and assessment /treatment of children.

Conicar was not *used for respite care* during 2003 (the year Rainbow Lodge opened). However, during 2004 one child had 6 periods of respite care, each lasting 3 days.

While no children required 'core-treatment' (i.e. *assessment/treatment*) during 2002 or 2003, 2 children have used this service in 2004. This indicates a continued reliance on specialist hospital care for children in the Board area.

### **Impact on Other Community Family Support Services**

All senior managers gave information which reflected the position across the Board area.

Within Causeway Trust children had not previously been able to access any other services (ie their needs were such that they could not be matched to carers within the family based community respite care service).

Children within Causeway have access to a community learning-disability nurse employed on a part-time basis by adult services and have no other specialist family support.

There is no residential provision for children with these disabilities in Causeway.

Homefirst Trust has a much wider range of family support services such as Crossroads, Barnardos ('Cherry Lodge' which is a 3-bed respite unit and special support service) and access to 4 full-time community nurses for learning-disability employed by adult services. The Trust also has a specialist 8-bed respite unit called 'Whitehaven' which has on occasions provided both short and long-term residential care for children. In addition, a team of 3 full-time children's community behaviour nurses provides a support service for children with severe learning disability and challenging behaviours.

The provision of services at Rainbow Lodge has created some tangible easement in family support services already used by the children (eg 3 children in total have reduced the level of service use in Crossroads by 20 hours per week). Additional new placements for 7 children have been opened-up within Cherry Lodge and 2 new placements in Whitehaven, but this realignment of services has been on a relatively small scale.

Children within Homefirst Trust who were not previously receiving services are now able to access Family-Support because of the establishment of Rainbow Lodge.

It is important to note that children in Causeway Trust are not able to access any of the range of specialist family support services available to children with similar needs in Homefirst.

### 3.4 CHILDREN'S EXPERIENCE OF THE SERVICE

#### 3.4(i) Unit Environment

The Service Specification for Rainbow Lodge states that:

*“The building, furnishings and décor of the unit should be domestic in size and character. Children should experience their environment as ‘ordinary’ and similar in terms of furnishing and equipment to the homes of their peers. Homeliness extends beyond the fabric and style of the building and staff are responsible for the ambience of warmth and hospitality. They are also responsible for ensuring the environment is safe and healthy.”*

Over the past 18 months, staff at Rainbow Lodge have had the task of changing the physical environment from that of a functional purpose-built unit to “a homely and safe environment”. Over half of the professionals who responded to our investigations stated the unit was homely, colourful and secure.

The unit has recently benefited from volunteers who painted wonderful murals on the walls. The children's bedrooms are each individually decorated with the children's individual personality and interests evident, demonstrating a respect for the children's sense of identity.



As a specialist children's unit Rainbow Lodge has specific facilities to meet the needs of the children (e.g. the bathroom, ball-room and sensory rooms):



The unit has also developed a safe outdoor play area:



### 3.4 (ii) Care Planning

The Service Specification Standard for Rainbow Lodge states that:

*“Planning is a process involving continuous assessment, objective setting and regular review. Children and their carers must be included in all stages of the process.”*

The ongoing care planning process for every child is multi-disciplinary in nature and it is often the case that plans are established before children enter units such as Rainbow Lodge. The complex needs of these children are very well known to a group of professionals who work with them.

#### **Parents/guardians**

responses to questionnaires demonstrated that the majority of their children had a care plan. Most of the parents stated that they felt involved in planning for their child's care.

Similarly, parents/guardians agreed that they were also involved in reviewing their child's care plan. However, they stated that they were concerned about what services are available for children after they reach 18 years.

**Professional** responses were generally positive, however a quarter were less so. Problem areas identified included concerns about the absence of an assessment bed, children's transition into adult care and no facility for "move on" if the children's level of challenging behaviour diminishes. Parents added that Rainbow Lodge would be a 'hard act to follow'. Both parents/guardians and professionals agreed that the children were subject to "planned care through ongoing assessment and regular reviews", however there were some concerns regarding the absence of an assessment bed and the need for transition planning.



### 3.4 (iii) Unit Staffing

Information on unit staffing is based on most recent discussions with the Head and the Assistant Director responsible for the unit and the document "Hugomont Drive, Statement and Purpose", June 2003.

The staffing structure within the unit (See: Figure 2, pg. 26) is markedly different from that, which existed in June, 2003. There is no longer a Deputy Manager (who would have been a Senior Nurse).

Unit staff operate within 5 primary care teams each of which has a team leader (who may be either social work or nurse trained), 1 nurse and 2 or 3 support workers. Each team is responsible for perhaps 3 or 4 children.

Some of the children who have more complex needs have a team leader as their key worker.

Nurse practitioners may also take on the key worker role for less children but unlike care facilitators they hold no additional organisational management responsibilities within the unit.

While some of the children have one key worker, other children may have the whole team as their 'key worker' with a named worker responsible for child contact.

During the period of investigation, some support workers in the unit had NVQ Level 2 or Level 3 awards. These are both competency and practice based qualifications.

Within the Board area there are 2 additional respite care units who have similar children in terms of their needs, and some children who are medically frail. One is operated by a voluntary agency and one by Homefirst Trust. At time of publication, all units are required to have NVQ Level 3 as their lowest aspiration for achievement by non professionally qualified staff. One of the units has a member of support staff trained to NVQ Level 4. The Registration and Inspection Reports for the unit have recommended that all support staff should have at least NVQ Level 3 training.

In order to ensure equity across the Board area NVQ Level 3 should be considered to be a minimum requirement to be commenced within a 2 year period from commencement of employment. The behaviour of the children can be unpredictable. While units who have care of children with similar needs maintain a high staff/child ratio, care for any particular child and combination of children must be the responsibility of the manager.

One to one contact between staff and child (or indeed higher) may be required to

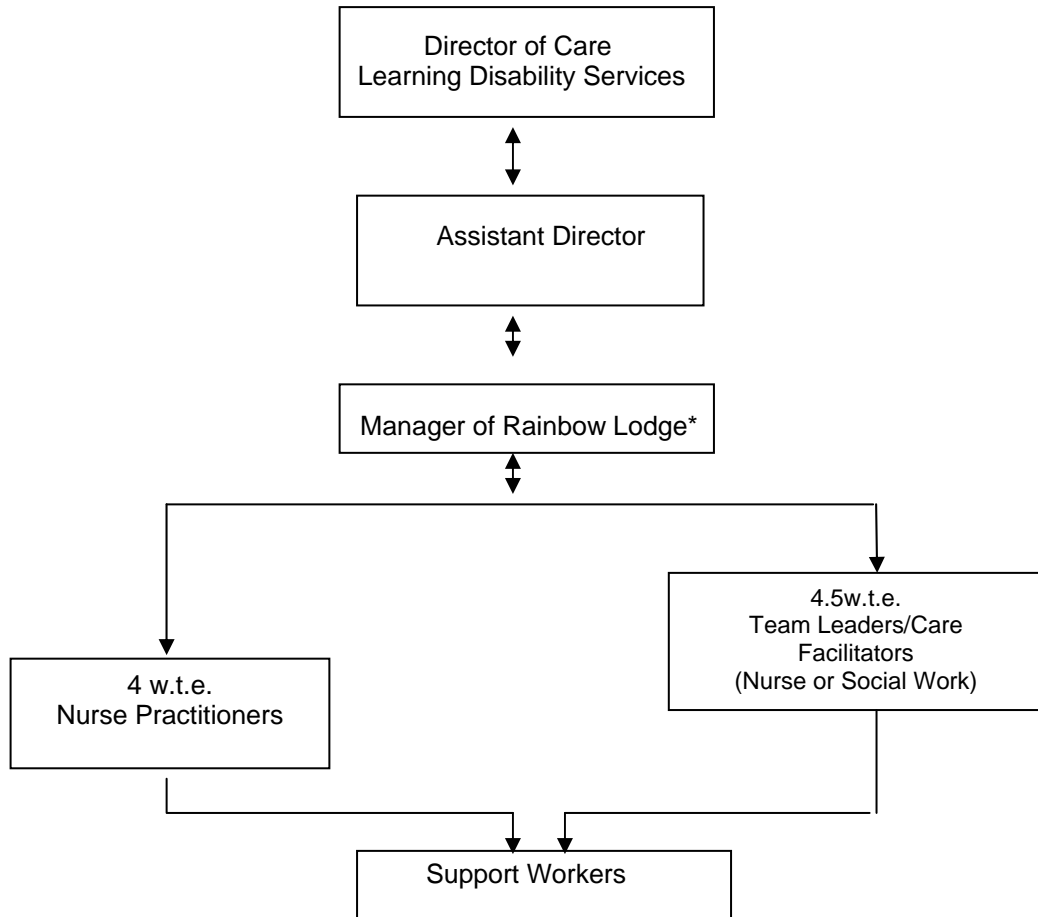
meet the needs of such children.

In terms of staffing ratios, a few professionals were concerned that the staff to children ratio needed to be higher (i.e. 1:1)

Some professionals suggested that unit staff may have limited understanding of the different roles and responsibilities according to placement type (i.e. permanent care, shared care and respite care) within the unit.

The concept and application of parental responsibility and corporate parenting (which in part determines the roles and responsibilities assumed in the unit) is highly complex and may need clarification. There may be need of formal inter-agency training involving all staff levels which will focus on and clarify the roles and responsibilities of Challenge, NHSSB and the Trusts.

**Figure 2: Organisational Structure in Rainbow Lodge**



\*In February 2006 the unit manager anticipates completion of ongoing studies to achieve a BSc (Honours) in Applied Psychology which will enable him to develop behaviour modification programmes.

### 3.4 (iv) Working Relationships

Effective communication is a key requirement within this field and is facilitated by good networking and partnership building.

*Parents/guardians* referred to the “excellent staff” and the “satisfactory” communication between themselves and unit staff. Half stated that staff are very approachable and a third referred to the availability and the opportunity to speak to them in person. Additionally, 4 referred specifically to receiving ‘up-to-date’ and relevant information/reports about routine and relevant occurrences recorded during their child’s stay.

Most *professionals* reported that links are created, maintained and partnerships are facilitated with carers, relatives and other key professionals. A fifth of professionals reported that communication and links with other professionals are a useful and effective aspect of the unit’s service. Many made reference to the accommodating staff and approachability of managerial staff.

In additional comments, allied health professionals stated that they only hear by ‘word of mouth’ from parents about the children and as such, there is unsatisfactory communication between themselves and unit staff.

Allied health professionals also pointed out that many of the children in Rainbow Lodge are using PECS as their communication system and there is no indication of this in the Methods of Intervention being reported by unit staff. The Unit staff appear not to know the children are using this system in schools and allied health professionals blame a lack of communication for this.

There is a need for unit staff to make contact with each of the professionals who are usually based in the children’s schools (OTs, speech and language therapists and physiotherapists) to discuss and plan for the needs of each child cared for in the unit.

## 4) RECOMMENDATIONS

The following recommendations deal with operational (4.1) and strategic (4.2) matters.

### 4.1 OPERATIONAL RECOMMENDATIONS

Recommendations of an operational nature outline best practice in regard to day-to-day activity within Rainbow Lodge.

#### *Target Group and Configuration*

Findings suggest that the 8-bedded unit meets many of the environmental and care statement of purpose requirements outlined by the Board. Currently, the majority of referrals at Rainbow Lodge are for respite however children requiring this part of the service currently only use a quarter of the beds in the unit. The original service specification identified four beds for this purpose.

1. The Board and Trusts should review the balance of services in regards to bed allocation within current resource allocation. Present provision of respite, assessment and treatment beds should be reviewed with reference to the Unit's Statement of Purpose.

#### *Range of Services*

The facility provides for the co-ordination and/or delivery of specialist services for children with a learning disability and severely challenging behaviour. Review evidence has highlighted issues about the appropriate balance of service provision, the levels of respite, assessment, treatment and outreach which the unit provides.

2. The capacity to deliver the original objective of providing an assessment bed as well as behaviour intervention programmes must be reviewed.
3. Multi-disciplinary outreach working should be developed by Challenge and the Trusts (with regard to the Unit's Service Specification) involving psychology, community nurses, social work and other professionals to support children and their families and to facilitate the continuation of behaviour programmes in the community.
4. The application of the referral criteria for challenging behaviours should be reviewed, standardised and protocols established.

This should involve Challenge, Behavioural Nurses, Social Workers and Clinical psychologists who could be involved prior to referral and should report to the assessment panel.

### **Staffing**

The Unit provides a core staff team which consists of social work, nursing and ancillary staff. Provision exists to support a range of services including therapy, psychology and psychiatry.

5. The Trust in conjunction with Challenge should review the current arrangements for the management of the home. This should specifically make reference to the management and the professional leadership of the home.
6. Challenge and Trusts should review the adequacy of the present in-reach to the service giving consideration to the clinical and psychological treatment needs of service users.
7. In light of current training trends, Challenge should require staff to commence N.V.Q. level 3 as a minimum within 2 years of employment in the unit.

8. Managers and care staff in the unit should participate in a half-day joint workshop with staff from both Trusts to promote cooperative working and partnership and to explore the future of the unit based on evaluation recommendations.

## **4.2 STRATEGIC RECOMMENDATIONS**

Recommendations of a strategic nature outline best practice in regard to legislation and strategies which determine the operations and procedures of Rainbow Lodge.

### **Acute Services**

The service is complemented with access to specialist acute provision for a small number of children with mental health and complex health-needs.

9. The commissioning of specialist hospital care provision for children who require assessment and treatment in a hospital environment should continue. Considerations such as the appropriate volume, type and protocols for use must be undertaken.

### ***Planning for Transition***

The Unit provides for children up to the age of eighteen. Transition to adult services must be carefully planned and managed for children from the age of fourteen.

10. As all six of the children with permanent residence are above the age of 14 years and will soon need alternative provision, a review of community residential, permanent and respite care, and other family support provision for young adults with severe learning disability and challenging behaviours should be undertaken between adult and children's services in the Trusts.
11. This must include a review of existing protocols and the development of a model of transition planning which will achieve continuity of care for young people within the current environment of scarce resources.

### ***Location***

The use of the unit by Board residents, particularly in relation to respite shows an inequitable distribution.

12. The Board and Trusts should review and, if necessary, renegotiate the proportionate access to/utilization of services.

### ***Education***

The level of educational attainment amongst the children was high. Co-operation and protocols with the NEELB are essential to maintain high standards of educational attainment.

13. The evaluation report should be shared and discussed with the NEELB.

### ***Monitoring***

The Boards responsibility for inspecting the Unit is primarily discharged through the Health and Personal Social Services Regulation and Improvement Authority (HPSSRIA).

14. HPSSRIA should be advised of the evaluation and its recommendations.

# APPENDICES

## **GLOSSARY:**

### **Allied Health Professionals**

Allied health professionals are health care practitioners with formal education and clinical training who are certified, registered and/or licensed. They collaborate with physicians and other members of the health care team to deliver high quality patient care services. (Health Professional Network)

### **Complex Health Needs**

Wake (1997) stated that 'profound and multiple disability could be construed as referring to an individual who requires maximum assistance in all aspects of everyday life, in terms of 24 hour care and supervision...the person may have difficulty in communication, eating, drinking and mobilisation'. The children will have physical disabilities and/or sensory impairment and this often includes a range of additional complex health needs e.g. recurrent chest infections, epilepsy. University of Ulster Report, 1998 – Children with a Learning Disability and the NHSSB. Service Specification (2000) (will add to the continuity of the evaluation findings).

### **Learning Disability**

"A lifelong impairment of intelligence which significantly affects social functioning. The impairment cannot be reversed but each person's individual learning ability, skills and quality of life can improve". (Murray and Heatherington, 1998.)

### **Looked After Children**

This terminology is used within the Children Order Arts. 25(1) (2) and (5) and refers to 'any child who is in the care of a Board or provided with accommodation by a Board for a continuous period in excess of 24 hours.

### **Parental Responsibility**

The Children Order (Article 6) defines this as all the rights, duties, powers, responsibilities and authority, which by law a parent of a child has in relation to the child and his property.

### **Severely Challenging Behaviour**

"Behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to, and use of ordinary community facilities". (Emerson et al, 1987)

This definition is used within the Service Specification, 2000 and was adopted by the Mental Health Foundation in “Don’t Forget Us” (1997) in respect of Children with Learning Disability.

### **Severe Learning Disability**

In addition to having a learning disability, the person has an IQ of less than 55.

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## QUESTIONNAIRES