Review of Barretstown Gang Camp

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Summary

The Chief Executive Officer Group of the Health Boards / Authority nominated a group to consider an application made to them by Barretstown Gang Camp for financial assistance.

The group comprised of:
1. Mr Seoirse O hAodhna, Finance Officer, North Eastern Health Board
2. Ms Priya Prendergast, General Manager, Community Services, Western Health Board
3. Dr. Marie Laffoy Specialist in Public Health Medicine, Eastern Regional Health Authority.

The group met on three occasions and visited Barretstown twice. Consultation took place with medical oncologists and Dr. G. Kiernan who recently undertook a PhD. thesis on Barretstown Gang Camp.

The main aspects examined were:
1. Strategic focus and effectiveness of the Camp
2. Health issues
3. Child welfare
4. Finance.

The conclusions and recommendations of the Group are:

1. Research indicates that Barretstown Gang Camp provides excellent psychosocial support to children with cancer.

2. It is a well run, beneficial organisation that should be considered for funding for children with cancer and serious haematological disorders. Funding should be on the basis of a Service Agreement, which identifies the quantum of service provision (cost per Irish child with cancer or serious haematological disorders) and on the basis that between 90-100 Irish children would attend the Camp each year.

3. On the basis of activity and cost information, the expected annual outlay is in the order of IR£150,000 for the children’s camps and an additional IR£100k. for the siblings camps. We recommend that priority for funding is the children’s summer camps (IR£150,000). The preferred method of funding is through the South Western Area Health Board.

4. The overall strategic focus of the Camp is being redefined. This is a welcome development. The Camp will consider whether it will cater for ‘serious illness’ or ‘chronic illness’. In this regard the future of diabetes camps is an issue. There is no doubt that the Camp has built-up strengths in relation to cancer children. Catering for children with cancer is also where the greatest health and social gain can be achieved.
5. Barretstown Gang Camp, though a valuable service, should not be seen as the solution to the psychosocial needs of children and families with cancer. It is one of possible approaches and does ease the burden. Other approaches are also needed.

6. The Camp should ensure that the strictest protocols to protect potentially immunocompromised children against avoidable infection should always be undertaken e.g. vaccination against meningitis C, ensuring staff are adequately protected against hepatitis B (i.e. post vaccination status is checked). These procedures should be regularly audited

1. **Introduction**

Barretstown Gang Camp recently made an application to the Chief Executive Officer Group of the Health Boards for financial assistance. Mr David Strahan, Chief Executive of Barretstown Gang Camp, sought a yearly per capita grant of 75% of the direct costs for each of the Irish children and their families who attend Barretstown Camp.

The health board / health authority chief executives nominated a group to pursue the proposal and to report to them.

The group comprised:
4. Mr Seoirse O hAodhna, Finance Officer, North Eastern Health Board
5. Ms Priya Prendergast, General Manager, Community Services, Western Health Board
6. Dr. Marie Laffoy Specialist in Public Health Medicine, Eastern Regional Health Authority.

The group met on three occasions and visited Barretstown twice. Consultation took place with medical oncologists and Dr. G. Kiernan who recently undertook a PhD. thesis on Barretstown Gang Camp.

The main aspects examined were:
5. Strategic focus and effectiveness of the Camp
6. Health issues
7. Child welfare
8. Finance.

2. **What is Barretstown Gang Camp?**

Barretstown Gang Camp is modelled on the “Hole in the Wall” camps in the US. It was founded by Paul Newman in 1994 to provide psychosocial support services to children with cancer and serious illness and to their siblings and parents. It provides bereavement programmes for children and adults. Recently it established an educational diabetes camp. The aim is to provide therapeutic recreation in a challenging but supportive
environment so as to improve self-esteem, coping skills and confidence of seriously ill children.

There are eight distinct components to the Camp:
1. Creativity: music, theatre
2. Instruction: woodwork, canoeing
3. Semi-structured: quest evenings, walk on wild side
4. Cottage related: cleanup, cottage chat
5. Socio-cultural: meeting others
6. Skill acquisition: special projects
7. Individual attention: photography, archery

2.1 Activity and Throughput

In 2000 there were 1,110 campers of which 660 (60%) were Irish (450, 75% from the Eastern Region). The remaining campers lived in Northern Ireland (2%), Great Britain (13%), former Eastern Block countries (11%), other European countries and the US (14%).

Of the 660 Irish campers:

- 103 (15.6%) attended the cancer, immunology and siblings programme
- 125 (18.9%) attended family camps
- 302 (45.8%) attended bereavement camps and
- 130 (19.7%) attended teen support camps (cancer and diabetes).

Summer camps cater for children (aged 7-16 years) and last 10 days. Each child is chaperoned by a “cara”. Family camps take place in Spring and Autumn. There is no costs to participants.

3. The Evidence: The psychosocial impact of cancer on patients

The report “Cancer Support Services in Ireland: Priorities for Action”, (1999) recommended that each health board / authority should develop a strategy to manage the psychosocial burden of patients diagnosed with cancer (1).

Psychosocial distress in patients with cancer can lead to adverse clinical outcomes. Distress can range from normal feelings of anger, shock and sadness to more severe reactions of a psychological or psychiatric disorder (2,3). Parents of a child with cancer can suffer high levels of emotional distress and anxiety including problems allocating time between caring for their sick child and maintaining the family unit (4,5,6,7). Siblings of a child with cancer may have difficulties in adjustment after the diagnosis and experience similar levels of distress as the sick child (8,9).
The psychological response to cancer, such as ‘fighting spirit’ or an attitude of ‘helplessness / hopelessness’, can be a prognostic factor for survival. Severe depression is linked to a reduced chance of survival. Responses of helplessness / hopelessness and depression should be treated vigorously to improve quality of life and optimise survival.

Families can maximise their role in caring for the sick family member when they learn to cope with the life threatening illness (11). Addressing the family’s psychosocial needs can improve quality of life, as caregivers with high levels of anxiety and depression are unlikely to be able to provide effective support to the patient. Support groups are effective in reducing psychological difficulties and emotional problems in patients with cancer (12). Therapeutic recreation based camping is increasingly being recognised as an intervention to meet the adjustment needs of seriously ill children and their families.

Outcome measures of cancer treatment include quality of life and not survival alone (10). The management of each patient’s psychological state should be an integral part of their cancer care and no patient with distress should go untreated.

3.1. **The Evidence: Effectiveness of Barretstown Gang Camp**

Between 1997-1999 an evaluation of Barretstown Gang Camp was undertaken by Dr. G. Kiernan for a PhD thesis.

The research examined the nature and effectiveness of the Camp. Though Camps, like Barretstown, are increasingly recognised there was little information regarding their effectiveness. This study aimed to address this issue. Qualitative and quantitative methods were used. Information from the campers and parents was obtained two weeks before participating, two weeks after participating and six months after participating. Feedback in relation to the Camp’s organisation, strategies of Fun, Challenge, Success and Reflection was obtained to establish the impact of the camp on the child’s well-being both short term and long term. Questionnaires contained formal measures to identify changes in children’s self-esteem, reported affect, physical symptoms and quality of life.

The main results were:

- Children felt the camp to be fun and enjoyable. Higher levels of fun were associated with higher levels of success and reflection

- Participation in the Camp was associated with benefits in:
  - Physical functioning (symptom reduction)
  - Social functioning (interpersonal and peer relationships)
- Psychological functioning (affect as it pertains to physiological hyper-arousal, intrapersonal attitudes and self-esteem as it pertains to global self-worth and social acceptance - longer term only).

  - The camp was more beneficial for some groups, notably younger children and those with an illness

  - The acquisition of cultural related skills was an added benefit.

  - Children’s views of the Camp related to its fun aspects, absence of worries about their stay, homesickness, activity-related skills, social benefits, psychological benefits and multiculturalism.

The main conclusion of the research was that Barretstown Gang Camp should be considered as a complementary intervention as opposed to a panacea for enhancing children’s and siblings’ adjustment to chronic illness.

The Camp facilitates measurable improvement in specific aspects of the child’s and siblings’ adjustment to illness but it does not provide the complete solution and cannot be considered to completely address the psychosocial needs of children with serious illness.

Additional research is needed to assess possible long term medical and psychological effects of Camps like Barretstown, in particular their possible long term effects on physical outcome of the illness.
4. **Funding and Costs**

Barretstown receives the majority of its income from fundraising / corporate donations. In 2001 it received £50,000 form the Department of Health and Children via the ERHA. It cost £2.079m to run the Camp in 2000. The total cost of Irish participants in 2000 was £865,385.

5. **Assessment of standards at Barretstown: ‘National Standards for Children’s Residential Centres’**

A number of the standards included in the *National Standards for Children’s Residential Centres* booklet introduced by the Department of Health and Children were used to assess the strengths and weaknesses of the services and operational procedures provided in Barretstown. These included:

- Purpose and Function
- Management and staffing
- Children’s rights
- Planning for Children and Young People
- Care of Young People
- Safeguarding and protecting Children
- Health Premises and Safety.

A full assessment of each of criteria is given in Appendix 1. In general, there were comprehensive and excellent policies and procedures for permanent and contract staff, volunteers, Activity and Unit leaders and Programmes. In summary Barretstown has:

1. A written mission statement of purpose and function that accurately describes what the Centre does and the manner in which care is provided. There was very good evidence that those working and using the camp understand the purpose and the function of the services provided at Barretstown.

2. The Centre is well managed and staff are organised to deliver the best possible care for young people. The Centre is managed by a Chief Executive Officer and has a Board of Management that oversees its work.

3. The rights of young people are reflected in all Centre policies and care practice and the children and their parents know what their rights are. Young peoples views are sought when decisions are being made that effect their daily life this is normally via their ‘Cara’. Young people are able to express concerns or complain about their care. The role of the Cara
is to be supportive and a friend in the context of the placement and children are encouraged to share concerns with these individuals.

4. The Centre Manager satisfies himself that suitable children attend the camp and that the camp will meet their needs. The Centre has a clear policy and agreed procedures, describing the process of admission. One of the basic criteria for admission is the individual’s state of health. Children must be well enough to participate in all programmes. The majority of referrals have heretofore come from Our Lady’s Hospital for Sick Children, Crumlin but similar referrals from Oncology Units in major hospitals throughout the country will now be accepted.

5. Young people are cared for in a manner that respects and takes account of their wishes, preferences and individuality.

6. The emotional life of young people in the care of the Centre is given particular attention.

7. The Centre is kept in good structural repair and decorated to a standard which creates a pleasant ambiance.

8. There is always a responsible adult available to the children who is capable of understanding and supporting them during their placement.

9. The Centre has a written policy on safeguarding young people in the Centre.

10. From the information provided and an inspection of facilities we consider that the health needs of children are assessed and generally met in Barretstown. There is a well equipped medical centre.
5.1 Specific Health issues

- The young person has a medical assessment by a paediatric specialist on admission (usually an oncologist) if he/she is on medication. Otherwise the assessment is undertaken by a nurse who has training in oncology and in first-aid.

- There is an agreed referral system to the camp. Referrals are on the basis that the child is well enough to participate. They are made the child’s medical consultant (usually a medical oncologist). The selection process appears to work well as there has only been one admission to St. John’s ward, Our Lady’s Hospital for Sick Children (OLHSC), and this was precautionary.

- Medical records are modelled on those used in OLHSC. These are very comprehensive and include:
  - general information e.g. medical condition and prognosis
  - special requirements e.g. central line, walking, eating, dietary restrictions
  - immunisations, recent contact with infectious diseases (chicken pox and measles)
  - allergies
  - written parental consent for treatment
  - prescribing and dispensing data
  - discharge report.

- Accident prevention policies are developed and there is an adequate minor injury treatment facility.

- There is a no smoking policy in the camp.

- In relation to health protection: relevant staff have hepatitis B vaccination and police clearance.

- Doctors working in the camp are usually from abroad. They are covered for medial defence and registered with the Irish Medical Council. It has not been possible to attract Irish doctors to work in the camp. This is said to be due to their high work loads.

5.2 Specific Financial issues

The full financial review is contained in Appendix 2.

The camps are split into two groups – Spring/Autumn and Summer. The Spring/Autumn camps are of 3 - 4 days duration and are week-end family camps i.e. parents and siblings
attend as well as the affected child. The summer camps are of 10 days duration and are for the affected children only.

Barretstown refer to the “Camper Days” in analysing their activity. Camper Days are the number of days that any attendee is present at Barretstown. Through an analysis of the costs and activity data for 2001 we have ascertained that the cost per Irish Camper Day for the Spring/Autumn camps is IR£233 and for the Summer camps is IR£160.

An analysis of the expected cancer related Irish attendees in 2001 and the camp costs gives the following matrix:

<table>
<thead>
<tr>
<th>Table</th>
<th>No. of Irish Cancer Attendees</th>
<th>No. of Camper Days</th>
<th>Cost per camper day</th>
<th>Total cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spring/autumn</td>
<td>272</td>
<td>836</td>
<td>IR£ 233</td>
<td>IR£ 194,788</td>
</tr>
<tr>
<td>Summer</td>
<td>94</td>
<td>940</td>
<td>IR£ 160</td>
<td>IR£ 150,400</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>366</strong></td>
<td><strong>1,776</strong></td>
<td></td>
<td><strong>IR£ 345,188</strong></td>
</tr>
</tbody>
</table>

The above table shows the costs the 2001 attendees from Ireland who are cancer sufferers or parents and siblings at IR£ 345,188.

### 5.3 Proposed Options for funding

The financial findings support the view that the Barretstown project is a deserving charity which provides positive benefits and should be considered for funding. Our view is that the 10 day summer camps which are focussed fully on the ill child with cancer should be considered for full funding and this is the priority. The shorter Spring/Autumn family weekends which include parents and siblings as well as the child may be considered for lesser funding. We propose the following funding structure

- **Summer Camps** - 100% (first priority)
- **Spring/Autumn Family Camps** - 50% (second priority)

The expected cost of subvention of cancer related Irish attendees for a full year is:

<table>
<thead>
<tr>
<th>Table</th>
<th>No. of Irish Attendees</th>
<th>No. of Camper Days</th>
<th>Cost per Camper Day</th>
<th>Total Cost</th>
<th>Proposed Subvention Rate</th>
<th>Cost of Subvention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spring/autumn</td>
<td>272</td>
<td>836</td>
<td>IR£ 233</td>
<td>IR£ 194,788</td>
<td>50%</td>
<td>IR£ 97,394</td>
</tr>
<tr>
<td>Summer</td>
<td>94</td>
<td>940</td>
<td>IR£ 160</td>
<td>IR£ 150,400</td>
<td>100%</td>
<td>IR£ 150,400</td>
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<td></td>
<td><strong>IR£ 345,188</strong></td>
<td></td>
<td><strong>IR£ 247,794</strong></td>
</tr>
</tbody>
</table>

The cost of subvention for a full year is IR£ 247,794
The selection of Irish participants is managed through the Paediatric Oncology Department of OLHSC. This would lead us to suggest that any funding from the health boards should be managed on either of the two following bases:
Funding from the DoHC managed through the South Western Area Health Board; or
Funding from the DoHC managed through a restricted fund at Our Lady’s Hospital for Sick Children.

It is suggested that to make each health board responsible for funding the participants from their specific area would lead to an unnecessary level of bureaucracy.

We would suggest that any funding should be given on the condition of assisting at least 94 Irish children during the summer camp period.

6. Conclusions and recommendations
7. Research indicates that Barretstown Gang Camp provides excellent psychosocial support to children with cancer.

8. It is a well run, beneficial organisation that should be considered for funding for children with cancer and serious haematological disorders. Funding should be on the basis of a Service Agreement, which identifies the quantum of service provision (cost per Irish child with cancer or serious haematological disorders).

9. On the basis of activity and cost information, the expected annual outlay is in the order of IR£150,000 for the children’s camps and an additional IR£100k. for the siblings camps. We recommend that priority for funding is the children’s summer camps (IR£150,000). The preferred method of funding is through the South Western Area Health Board.

10. The overall strategic focus of the Camp is being redefined. This is a welcome development. The Camp will consider whether it will cater for ‘serious illness’ or ‘chronic illness’. In this regard the future of diabetes camps is an issue. There is no doubt that the Camp has built-up strengths in relation to cancer children. Catering for children with cancer is also where the greatest health and social gain can be achieved and the best value for investment. We do not recommend funding for diabetes camps.
11. Barretstown Gang Camp, though a valuable service, should not be seen as the solution to the psychosocial needs of children and families with cancer. It is one of possible approaches and does ease the burden. Other approaches are also needed.

12. The Camp should ensure that the strictest protocols to protect potentially immunocompromised children against avoidable infection should always be undertaken e.g. vaccination against meningitis C, ensuring staff are adequately protected against hepatitis B (i.e. post vaccination status is checked). These procedures should be regularly audited.
1. **Appendix 1:** Assessment of standards at Barretstown: ‘National Standards for Children’s Residential Centres’

1. **PURPOSE AND FUNCTION**

**Standard**

Check that the Centre has a written mission statement of purpose and function that accurately describes what the Centre does and the manner in which care is provided.

**Criteria**

- ✔ Statement is available, assessable and understood. **There is considerable evidence that the mission of Barretstown is available and understood by all full time staff.**
- ✔ Statement is up to date with the responsibility for who updates this clearly defined. **The Director of Communications has responsibility for updating the Mission Statement, which is reviewed every few years. The last service review was carried out in the past year.**
- ✔ Statement is available in a form that is accessible to young people and their families **There is evidence that the Mission Statement is included in all information packs**
- ✔ Statement lists the key policies that are in place
- ✔ Staff are familiar with the statement and understand it
- ✔ Day to day operations of the Centre reflect the statement, purpose and function
- ✔ Are the needs of psychosocial supports for cancer children met

**There was very good evidence that all those working and using the camp understand the purpose and the function of the services provided at Barretstown.**
2. **MANAGEMENT AND STAFFING**

**Standard**

The Centre is effectively managed, and staff are organised to deliver the best possible care for young people. There are appropriate management and monitoring arrangements in place.

**Criteria**

- √ Centre is managed by an appropriately qualified person **who is the CEO**.
- √ Centre has external management that oversees the work of the Centre
- √ Centre Manager(s) satisfies themselves that appropriate and suitable practice and operational policies are in place
- √ Managers have in place measures for assessing the quality and effectiveness of the services provided with a particular focus on outcomes. **There are testimonials from children, which is a measurement of the quality of the programmes and service. In addition, the Programme Director would use standards that form part of various Accreditation systems designed by a range of different organisations. This is because there is no specific system for this particular type of service. However, the standards used by Barretstown are those instituted by the American Camping Association. Other standards used by Barretstown are those used by organisations operating in Ireland and the (please refer to Appendix A).**
- √ Management registers any changes in relation to the person in charge to the Health Board
- √ There are procedures for noting significant events. **There is an Accident/Incident form and procedures are in place for the notification of significant events.**
- √ The Centre has adequate levels of staff to fulfill its purpose and function
- √ Staff are qualified and have the ability to communicate effectively with children. **Qualifications vary and may be different in respect of chaperones attending from overseas**
- √ All staff, students and volunteers are appropriately screened before taking up duty. **Screening consists of two written references from individuals who are not related to the applicant plus two additional telephone references, a completed police check, evidence of educational qualifications, a curriculum vitae plus testimonials. Once selected, staff also undergo Psychometric Testing.**
- √ All staff receive induction on appointment
- √ All staff members receive regular and formal supervision, details of which are recorded
- √ There is an effective link between supervision and implementation of individual care plans for children. **There is an evaluation based on the initial reference, which results in staff being matched appropriately to individual teams and individual children.**
- √ Staff meetings, hand over meetings and other meetings take place regularly to facilitate good communication, co-operation and consistency between staff in implementing programmes and plans
- √ That Management have support mechanisms in place for staff
- √ That the Employer ensures that provisions in relation to employment law are adhered to
- √ That there is effective ongoing staff development and training
- √ That recording systems are organised and maintained to facilitate management and accountability i.e. FOI Act, 1997. **All records regarding personnel and files relating to individual children are kept in a secure and safe place. Reports are written in a fair and objective manner.**
- √ That the quality of all records of decisions and reports taken by staff are monitored and appropriate action is taken to remedy deficiency and safeguard the interest of children
- √ That the Centre has clear Financial Management Systems and records
- √ What Risk Management measures are in place
- √ Who decides on management
3. CHILDREN’S RIGHTS

Standards

Rights of young people should be reflected in all Centre policies and care practice and those children and their parents know what their rights are.

Criteria

- √ Young peoples views are sought when decisions are being made that effect their daily life. Views are normally sought from children by their Cara.
- √ That the opinion and views of young people are sought and valued.
- √ That young people are able to express concerns or complain about their care. The role of the Cara is to be supportive and a friend in the context of the placement and children are encouraged to share concerns with these individuals.
- √ That there is a Complaints Procedure in place.
- √ That the Complains Procedure outlines what constitutes a complaint, how a young person can be helped make a compliant, who they can complain to both in and outside the Centre, the procedure to be followed and the appeals mechanism.
- √ That all serious complaints are notified to the Health Board. There is evidence that referrals about suspicion of neglect and disclosures of physical and sexual abuse have been made to the Health Board. All staff are familiar with the procedures in respect of reporting serious complaints. In respect of children coming from overseas staff in Barretstown follow procedures of the relevant country where such procedures exist by informing the link person.
- √ That complaints are recorded and taken seriously.
- √ That there are systems in place to monitor the instance and outcomes of all complaints.
- The Centre has a written policy on young people’s access to information in accordance with their age and level of experience. The Centre does not have a written policy on young peoples access to information, but there is a policy in relation to being as open and as facilitative as possible on an individual basis.
- That young people have access to information about their rights under the United Nations Convention of the Child, 1989 and under the Freedom of Information Act, 1997. There do not appear to be any policies in relation to children rights in this respect.
- √ That young people are given information verbally and in writing and are guided on how to exercise their rights if they wish.
- That young people and their families receive written information about their placement. While parents/guardians do not receive written information about their child’s placement they are given a verbal report by the child’s Cara. Additional information about camp activities is available via the Camp Magazine and the child’s personal journal.
- √ Is there follow up - What feedback is received. GP’s get a copy of accident and medical reports.

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4. PLANNING FOR CHILDREN AND YOUNG PEOPLE

Standard

Plans should state the aims and objectives of the placement and promote the welfare, interest and health needs of young people and address their emotional and psychological needs.

Criteria

- ✓ That the Centre Manager is satisfied that the placement is suitable and will meet the needs of the young person
- ✓ That the Centre has a clear policy and agreed procedures, describing the process of admission. One of the basic criteria for admission is the individual’s state of health. Children must be well enough to participate in all programmes. The majority of referrals have heretofore come from Crumlin but similar referrals from Oncology Units in major hospitals throughout the country will now be accepted.
- ✓ Young people and their families should be invited to visit the Centre before admission. There are annual Open Days.
- ✓ Young people are provided with age appropriate information describing all the aspects of the Centre
- ✓ Young people are assisted to understand the reason for and the purpose of their placement and know what to expect. Young people do not always understand why such a placement has been arranged. This is because they may have conditions such as HIV and it would not be appropriate to disclose the implications of their illness to them until they have received appropriate support and counselling. The young people are usually under the impression that the holiday break is because they have been seriously sick.
- ✓ Those referring young people have a clear responsibility to let the Centre have adequate information on Policies and practices should take account of the need to protect young people
- ✓ Placements are supported by a schedule based on the aims and objectives of the placement and identify how the placement will help support and promote the welfare of each person
- ✓ A written copy of this care plan is made available to the guardians of the young person on request.
- ✓ Young people should on discharge, have an exit interview/review and have opportunities to provide feedback to Centre staff. There is no system for an exit interview/review but children are given postcards on which they can write their comments. Barretstown relies on verbal reports and have developed a database, as there is a policy in relation to sending birthday cards.
- ✓ Contact with family members and significant others should be encouraged and facilitated in private
- ✓ Parents should be kept informed about any significant events in their child’s life during the placement
- ✓ Siblings should also have input where possible. The programme for siblings is specifically designed to deal with their issues such as guilt and anger. This programme is separate.
- ✓ Staff should be aware of the emotional and psychological needs of young people
- ✓ That all children will have access to specialist services during their placement if they require it
- ✓ Staff members ensure that all belongings, i.e. photographs, contacting address etc. are given to the young person on leaving the Centre
- ✓ That each young person has a permanent private and secure record of his placement. All records are kept in a locked cabinet. Children have individual lockers by their bed and can ask their Cara to care for other items.
- ✓ That records are written to a standard and a style defined by the Centre and are clearly expressed and free from stereotypes
- ✓ That case and care records are kept in a way that maintain the appropriate levels of privacy and confidentiality about young peoples circumstances
- ✓ Is there a consent form for parents/guardians
- ✓ What is the referral process
5. **Care of Young People**

**Standard**

Centre staff should relate to young people in an open positive and respectful manner with care practices taking account of young people's individual needs and respect for their social, cultural, religious and ethnic identity. Young people should have similar opportunities and leisure experiences to the peers and have opportunity to develop and pursue interests.

**Criteria**

- √ Young people are cared for in a manner that respects and takes account of their wishes, preferences and individuality
- √ The emotional life of young people in the care of the Centre is given particular attention
- √ Young people should know that there is a responsible adult available to them who is capable of understanding and supporting them during their placement
- √ Young people have the opportunity to maintain and develop interests and hobbies and participate in a range of leisure and recreational opportunities of their choice. **Activities are based on the concept of fairness rather than competition.**
- √ Young people have adequate quantities of nutritious and appetizing food and their preferences should be taken into account when planning menus. **Menus have had the approval of the Dietitians in Crumlin’s Children’s Hospital**
- √ Young people during their placement should endure the same opportunities as their peers and are not subject to any form of discrimination
- √ Disability is acknowledged and a positive approach to, and positive images of, disability are made available **There is an inclusive approach in respect of all children regardless of the extent of individual disabilities.**
- √ All staff should be made aware of the Centre’s policy on anti-discrimination and operate this in their daily practice
- √ Young people understand the behaviour expected of them
- √ The Centre should have a written policy on Bullying that promotes a positive and safe environment
6. **SAFE GUARDING AND PROTECTING CHILDREN**

**Standard**

Attention should be paid to keeping young people in the Centre safe, through conscious efforts designed to ensure a regime that promotes openness and accountability.

**Criteria**

- ✓ The Centre has a written policy on safeguarding young people in the Centre.
- ✓ The Centre’s policy should include
  - ✓ recruitment procedures
  - ✓ induction and ongoing training and supervision
  - ✓ an appraisal of staff
  - ✓ monitoring standards of care
  - ✓ staff understanding that part of their role in safeguarding children is to monitor colleagues practice and raise concerns as appropriate
  - ✓ complaints procedures
  - ✓ Advocacy support for young people. *There is no specific advocacy support for young people in the care of Barretstown apart from the ethos of the service, which is based on empowering individuals.*
  - ✓ children’s rights and participation
  - ✓ team teaching and working and informed therapeutic recreation
  - ✓ private access and communication by young people to others with a legitimate interest in their welfare
- ✓ Staff understand the policy and that it is carried out in practice
- ✓ The Centre has written guidelines on the nature of appropriate professional relationships between staff members and young people including one to one contact
- The Centre should have written policies and procedures agreed with the local Child Care Manager, within the local Health Board. *This criterion is not relevant at this point in time.*
- These policies and procedures should be consistent with the National Guidelines for the Protection of Children. *This criterion is not relevant at this point in time.*
- ✓ Staff members are under clear obligation to report any child protection concerns to the Centre Manager
- ✓ What system is in place in relation to taking on volunteers
- ✓ Is Garda clearance obtained prior to taking on new staff/volunteers
7. **Premises and Safety**

The premises and safety issues were reviewed using a predetermined 21 point checklist. In summary the buildings are in good structural repair. There is an annual maintenance budget approved by the board and a maintenance record is maintained. All procedures including up to date Health & Safety Statement and fire regulations have been complied with together with regular fire drills and accident reporting systems appear to be operating effectively. The insurance cover appears to be adequate.

**Criteria**

- The Centre is kept in good structural repair and decorated to a standard which creates a pleasant ambiance
- The furnishings and facilitates are adequate and sufficient for the young people living in the Centre
- The Centre is adequately lighted, heated, ventilated and has suitable facilities for domestic living
- The Centre has age appropriate recreational facilitates that are available to young people.
- That young people have access to space within the Centre where their personal belongings can be kept safely and securely
- That young people have either a room to themselves or space to be private or alone
- The Centre is adequately insured against accidents or injuries to children
- Repairs to the Centre are dealt with promptly and a record is kept of all such repairs, detailing the need for the repair and the action taken and the date of completion
- Managers have a programme of maintenance and capital works that will ensure that structural order is maintained
- The Centre has systems in place for reporting accidents and injuries
- The Centre has a Health & Safety Statement
- An appropriate number of staff are adequately trained in First Aid techniques
- Vehicles used to transport young people are road worthy
- All drugs and medicines are safely stored and secured in a secure cabinet to which young people do not have access. The administration of medication is properly recorded in line with Centre policy
- Adequate precautions are taking against the risk of fire, including effect means of escape, arrangement for detecting, containing and extinguishing fires and maintenance of fire fighting equipment
- Menus are approved by dieticians in Our Lady’s hospital for Sick Children
- Kitchen facilities have recently been inspected by environmental health officers and found to be suitable.
Appendix 2  Barretstown Gang Camp Fund Limited

Financial Review

1. Background.

1.1 Barretstown Gang Camp Fund Limited (“Barretstown”) is a company limited by guarantee without share capital. It is a registered charity in Ireland. Its principal activity is the operation of a summer camp for children with cancer and other life threatening illnesses. Barretstown was founded in 1994, to provide psychosocial support services to children with cancer and to their siblings and parents who have been affected by serious illness. Barretstown also provides bereavement programmes for children and adults and also provides a diabetes camp programme. By the end of 2001, a total of 6,381 children and family members from 23 countries will have attended the Camp.

1.2 The Governors and Directors of Barretstown include high profile members of the business and medical communities together with Paul Newman the US actor, who founded the organisation. According to the Audited Financial Statements the services of the governors, directors, solicitors and auditors are given free of charge.

1.3 In August 2001 Barretstown made an application to the Health Boards and the Eastern Regional Health Authority for support. The proposal states

“In order to continue to serve children, and to expand the service in the future to provide an even more extensive service, Barretstown would like to form a long term partnership with the Regional Health Boards and the Department of Health and Children. The partnership would take the form of Barretstown being sponsored by the health services to fill some of the needs identified in relation to a more holistic support approach for the management of cancer in Ireland – as outlined in the Cancer Support Services in Ireland – Priorities for Action document. Financial support would comprise a per capita subvention for Irish children and families served by Barretstown."

1.4 Barretstown provide their camps to children and families entirely free of charge including round trip transportation and provide medical supervision. The selection of Irish children to attend the camp is mainly through the Paediatric Oncology Department of Our Lady’s Hospital for Sick Children, Crumlin (OLHSC).
2. **Work conducted**

2.1 The financial study was undertaken to review the most recent financial reports of the company and establish its current financial position. This was done by reviewing the Audited Financial Statements for the three financial periods ending on 31 March, 1998, 1999 and 2000 and the Draft Financial Statements for the year ended 31 March 2001. The second part of the review was to establish the running costs of the Camp in relation to the Irish participants. This was done through a detailed review of costs, activity reports and costings of the Barretstown operation. The work was conducted in association with Mary Conway, Financial Controller of Barretstown and her staff.

2.2 A review was also undertaken under the heading of Premises and Safety. This was to ensure that the premises are suitable for the Residential Care of young people and that their use is in keeping with the stated purpose and to ensure that Barretstown has adequate arrangements to guard against the risk of fire and other hazards. Insurance cover was also reviewed.

3. **Review of the Financial Statements**


3.2 The following paragraphs review the Income and Expenditure statements for the 4 years together with the Draft Balance Sheet at 31st March 2001 showing the current financial position.

<table>
<thead>
<tr>
<th>Table A – Income and Expenditure Accounts for the 4 years to 31st March 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Error! Not a valid link.</td>
</tr>
</tbody>
</table>

* the fall in Management and admin costs in 2001 is due to a reallocation of expenditure elements

3.3 The unrestricted surplus represents a surplus on funds which can be used for general purposes. The restricted surplus represents a surplus on funds which are made on condition that certain capital works are carried out. They cannot therefore be used to fund day to day camp activities.
3.4 Income is mainly comprised of donations raised in Ireland and overseas. The overseas contributions to Barretstown are collected through the US based charity, The Hole in the Wall Gang Fund and also the UK based charity, The Barretstown Gang Camp Fund (UK) Limited. The charities have common objectives and activities. Over the 4 year period 49% of the income was donated by these charities. However, outside of a contribution of £50k to date from the South Western Area Health Board, Barretstown receives no ongoing support from the Irish health agencies, Paul Newman or any other institution or person.

3.5 Other income comprises mainly of rental income on the property of the Barretstown Castle Trust not utilised, circa 400 acres.

3.6 The company receives, free of charge, (a) the services of health care professionals and, (b) the use of the property and grounds at Barretstown Castle, from the Irish Government through the Barretstown Castle Trust (nominal rent of IR£ 1.00 per annum), (c) a significant contribution towards the cost of professional fees relating to the building programme by the Barretstown Castle Trust, and (d) the services of the governors, directors, solicitors and auditors. No monetary recognition has been reflected in the financial statements in respect of these items.

3.7 The Direct charitable expenditure represents the amount actually expended in the running of the camps. The fundraising and promotion expenditure consists mainly of the payroll and promotional expenditure associated with fundraising and the management and administration costs consist primarily of the payroll costs for senior management and administration staff.

3.8 Since 1994, Barretstown has invested IR£5 million in fixed assets of which IR£1 million was spent in the last 3 years. The cash balance at 31st March 2001 is IR£ 2.017 million. A substantial portion of the cash balance at 31 March 2001 represents donations made on condition that certain capital works are completed. Therefore, these restricted funds cannot be used for general purposes. The Financial Controller has indicated that it is intended to use these funds for the purposes for which they were donated.
4. **Review of the Activities**

4.1 This part of the review set out to establish the costs related to the running of the camps for the Irish children suffering from cancer and their families. We have not considered funding the other programmes.

4.2 The camps are split into two groups – Spring/Autumn and Summer. The Spring/Autumn camps are of 3 to 4 day duration and are weekend family camps i.e. Parents and siblings attend as well as the affected child. The summer camps are of 10 days duration and are for the affected children only.

4.3 Barretstown refer to the “Camper Days” in analysing their activity. Camper Days are the number of days that any attendee is present at Barretstown. Through an analysis of the costs and activity data for 2001 we have ascertained that the cost per Irish Camper Day for the Spring/Autumn camps is IR£233 and for the Summer camps is IR£160.

4.4 An analysis of the expected cancer related Irish attendees in 2001 and the camp costs gives the following matrix:

<table>
<thead>
<tr>
<th>Table C</th>
<th>No. of Irish Cancer Attendees</th>
<th>No. of Camper Days</th>
<th>Cost per camper day</th>
<th>Total cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spring/autumn</td>
<td>272</td>
<td>836</td>
<td>IR£ 233</td>
<td>IR£ 194,788</td>
</tr>
<tr>
<td>Summer</td>
<td>94</td>
<td>940</td>
<td>IR£ 160</td>
<td>IR£ 150,400</td>
</tr>
<tr>
<td>Totals</td>
<td>366</td>
<td>1,776</td>
<td></td>
<td>IR£ 345,188</td>
</tr>
</tbody>
</table>

4.5 Table C costs the 2001 attendees from Ireland who are cancer sufferers or parents and siblings at IR£345,188.

5. **Premises and safety review**

5.1 The premises and safety issues were reviewed using a predetermined 21 point checklist. In summary the buildings are in good structural repair. There is an annual maintenance budget approved by the board and a maintenance record is maintained. All procedures including up to date Health & Safety Statement and fire regulations have been complied with together with regular fire drills and accident reporting systems appear to be operating effectively. The insurance cover appears to be adequate.

6. **The case for funding**
6.1 Paragraph 1.3 sets out the general proposal from Barretstown for the establishment of “a long term partnership with the Regional Health Boards and the Department of Health and Children”

From a study carried out in conjunction with the Psychology Department at Trinity College the effects of the Camp appear to be very beneficial to the attendees with the following specific benefits:

i. Enhanced self esteem, confidence, coping skills and stress reduction resulting in less demand on carers.

ii. Positive changes in children’s psychological and social functionings

iii. While not accurately measured, the general literature is supportive of a reduction in the hospitalisation and treatment costs for children post camp.

7. Proposed Options for funding

7.1 The financial findings support the view that the Barretstown project is a deserving charity which provides positive benefits and should be considered for funding. Our view is that the 10 day summer camps which are focussed fully on the ill child should be considered for full funding. The shorter Spring/Autumn family weekends which include parents and siblings as well as the child can be considered for lesser funding. We propose the following funding structure

Spring/Autumn Family Camps - 50%
Summer Camps - 100%

Using the figures in Table C the expected cost of subvention of cancer related Irish attendees for a full year is:

<table>
<thead>
<tr>
<th>Table D</th>
<th>No. of Irish Attendees</th>
<th>No. of Camper Days</th>
<th>Cost per Camper day</th>
<th>Total cost</th>
<th>Proposed subvention rate</th>
<th>Cost of subvention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spring/autumn</td>
<td>272</td>
<td>836</td>
<td>IR£ 233</td>
<td>IR£ 194,788</td>
<td>50%</td>
<td>IR£ 97,394</td>
</tr>
<tr>
<td>Summer</td>
<td>94</td>
<td>940</td>
<td>IR£ 160</td>
<td>IR£ 150,400</td>
<td>100%</td>
<td>IR£ 150,400</td>
</tr>
<tr>
<td>Totals</td>
<td>366</td>
<td>1,776</td>
<td></td>
<td>IR£ 345,188</td>
<td></td>
<td>IR£ 247,794</td>
</tr>
</tbody>
</table>

The cost of subvention for a full year is IR£ 247,794
7.2 The selection of Irish participants is managed through the Paediatric Oncology Department of OLHSC. This would lead us to suggest that any funding from the health boards should be managed on either of the two following bases:

i. Funding from the DoHC managed through the South Western Area Health Board; or

ii. Funding from the DoHC managed through a restricted fund at Our Lady’s Hospital for Sick Children.

It is suggested that to make each health board responsible for funding the participants from their specific area would lead to an unnecessary level of bureaucracy.

7.3 We would suggest that any funding should be given on the condition of assisting at least 94 Irish children during the summer camp period.

8. Conclusion

8.1 Barretstown Gang Camp Limited is a well run and beneficial organisation that should be considered for funding. On the basis of activity and cost information, the expected annual outlay is in the order of IRE 250k. The preferred method of funding is through either the South Western Area Health Board or through OLHSC.
References