

# “Have cape will travel”: Captain Starlight in the Northern Territory

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## Abstract

This paper will share the experience of bringing a program that was well established in hospital settings in metropolitan Australia to regional and remote communities in the Northern Territory.

The Starlight Children’s Foundation has provided in hospital and outreach programs for over twenty years to children and young people with serious illness or chronic health conditions.

In 2006 Starlight expanded its outreach program to the Northern Territory. The program works alongside local Healthy Children’s Health Clinics to encourage attendance at the health clinics and help alleviate anxiety associated with health services. The program also incorporates the delivery of health promotion messages through entertainment.

In 2008 an independent evaluation of the pilot was undertaken to assess the acceptability and success of the program. The findings of this evaluation were then shared at an existing roundtable that brings together people from Aboriginal organisations, government, research groups and other services. The roundtable is designed to ensure the voices of Aboriginal people are strong in the setting of priorities and to help build collaborative relationships between organisations.

The program evaluation findings and recommendations for future program development are shared. The successes and learning provide a practical example for other organisations to consider in relation to extending their programs to work with Aboriginal people and the potential for collaboration with charities.

## Introduction

Starlight Children’s Foundation is a not-for-profit organisation that began in 1988 with the aim of brightening the lives of seriously and chronically ill children and their families. In achieving this aim the Foundation has implemented a series of innovative hospital and outreach programs focusing on positive distraction to enhance the wellbeing of children and young people with serious illness or chronic health conditions.

An essential element of Starlight’s programs is Captain Starlight. These highly skilled larger-than-life, fun filled characters bring the human touch, distraction and entertainment to ill children at a time when they need it most. In the eyes of the child, Captain Starlight is a super hero who brings laughter, games, jokes and all kinds of silliness into their lives and helps them forget they are unwell.

Acknowledging the needs of seriously and chronically ill children and their families living in Indigenous communities, Starlight expanded its Captain Starlight program in 2006, to include the Northern Territory. Captains regularly visit children at hospitals and clinics where it is estimated that between 90-95% of child patients and visitors are Aboriginal. Included in the Captains’ visits are the Royal Darwin, Gove and Alice Springs hospitals; the children’s clinic at Yirrkala and the paediatric clinic at Central Australian Aboriginal

Congress (Congress). In addition, as part of the remote and regional community visits, Captain Starlight periodically visits schools and child care centres.

The Captain Starlight program has continued to grow. Since its establishment in the Northern Territory Starlight have reached over 13,300 children and provided over 2,900 hours of entertainment.

In 2008 alone Starlight made 212 hospitals visits and travelled approximately 58,570kms in the Northern Territory. Additionally, 48 other health services were visited in the Northern Territory with the largest proportion being made up of indigenous groups. At nearly 1448 hours, the Northern Territory Captains delivered the highest hours of outreach entertainment in the nation.

More recently Starlight has broadened its scope in the Northern Territory to incorporate an element of education in response to an identified need in the area of hygiene and immunisation. The need arose after health workers identified that many of the Indigenous children visiting remote health clinics showed signs of anxiety associated with the equipment used to measure and track children's health, and were shy or indifferent to adopting recommended hygiene behaviours.

In response to this need, and with the help of the Coordinator for Health Promotion at the Royal Darwin Hospital and health workers at the Yirrkala health clinic, the Northern Territory Captains developed a series of half hour interactive shows aimed at promoting health and hygiene through fun and education. Elements addressed in the shows included:

- nose blowing
- using the bin to stop the spread of germs
- ear cleaning
- measuring height and weight
- washing hands.

The shows employ age appropriate music, dance and songs to educate and promote positive health messages while also modelling recommended health behaviours. The children are encouraged to join in and to mimic health behaviours such as nose blowing, using the bin to dispose of the tissue, and washing hands. Games such as 'musical statues', played out on measuring scales are used to distract children from their fear of measuring devices/medical equipment, by having the children engage with the equipment in a non-threatening and entertaining manner.

Early feedback indicated that the shows were having the desired impact with teaching and health clinic staff reporting reduced anxiety and less reluctance on the part of the children to engage in recommended health behaviours. In addition it appeared that the Captain Starlight program was associated with the increasing number of children and families attending health clinics on the days when the Captains were visiting.

In 2008 an independent evaluation was undertaken to assess the acceptability and success of the Northern Territory Captain Starlight program. The findings of the evaluation were shared at an existing roundtable bringing together people from the Aboriginal organisations government, research groups and other services. The roundtable ensured the voices of Aboriginal people are strong in the setting of priorities of Starlight's Captains program, and for helping to build collaborative relationships between organisations.

Since the evaluation Starlight has expanded its Northern Territory Captains program to include involvement from local Indigenous people. The program has been updated to include training and teaching in

infectious control as well as arts based activities to assist in promoting health behaviours in local communities.

## Summary of evaluation findings of the Northern Territory Captain Starlight Program

The evaluation of the Northern Territory Captain Starlight program was undertaken by the Cooperative Research Centre for Aboriginal Health (CRCAH). The evaluation focused primarily on the Captain Starlight activities conducted at Yirrkala and the paediatric clinic at Central Australian Aboriginal Congress. In order to enable comparisons between community health centre and hospital activities, the Royal Darwin, Grove and Alice Springs activities were also evaluated providing a richer picture of the Captain Starlight activities in the Northern Territory.

The evaluation sought to determine the acceptability of the Captain Starlight 'brand' in the Northern Territory; the impact of the Captain Starlight activities; and obtain suggestions for how the Captain Starlight activities can be improved to be more relevant and / or effective in remote and regional community settings.

The key questions asked in the evaluation included:

- Acceptability
  - To what extent do people recognise the Captain Starlight brand?
  - How well is Captain Starlight received by the community?
- Impact
  - Has the Starlight Children's Foundation improved attendance at clinics?
  - What are the impacts of Captain Starlight as entertainment?
  - What are the impacts of the health promotion messages?
  - Does Captain Starlight benefit / make a difference to the work of the health staff?
- Suggestions for improvement
  - How could Captain Starlight activities be improved to be more relevant or effective?
  - How often should Captain Starlight visit?

## Methodology

Document analysis, interviews and observations formed the basis of the evaluation.

### Document analysis

A number of documents were reviewed including the Starlight Children's Foundation brochures, background information sheets and the Starlight Children's Foundation website. These provided information about the history and context of the current Captain Starlight program.

### Interviews

Semi-structured interviews with a range of health service staff in community health centres, hospitals and child care centres were conducted in Darwin, Grove, Yirrkala and Alice Springs. In depth interviews were also held with each of the three Darwin based Captains. Opportunistic interviews and discussions were also conducted with child care centre, school and preschool staff, parents and community members

during the site visits. The interviews were tailored to respondents' experiences with the Program with questions being drawn from a questionnaire sent to health centres prior to the interview. These data were organised into agreed categories and emerging themes were identified. Opportunistic discussions with families or support people were recorded in a notebook.

### **Observations**

Observations of the Captains' performances, activities and interaction with the children and their families were undertaken on site visits to Yirrkala, Gove and Alice Springs. Photos were taken of the group activities held in the community health centres. Permission was gained from parents for the photos and copies of all photos taken back to the health and child care centres for display and distribution.

### **Ongoing feedback for program development**

A formative evaluation was employed. Evaluators regularly fed back findings and observations for the field visits to the Captains and their managers. This feedback provided opportunities for clarification, discussion and Program improvement to the end of the evaluation.

### **Limitations of the evaluation design**

Within the Yirrkala community conversations with parents were limited due to English not being the first language of some of the parents. Few parents in attendance, and a distressed and ill child also limited the number of parent conversations that could be carried out in hospital settings.

### **Strengths of the evaluation design**

The evaluation design was flexible and allowed for the evaluators to adapt to the circumstances and the location.

## **Findings**

With the exception of the comparative experiences of Captains between states and territories the findings are organised around the key questions examined in the evaluation.

### **The Northern Territory is different**

Interviews with the Captains identified several ways in which the children from remote and regional Northern Territory communities differ from the children Captain Starlight works with in other areas of Australia. The Captains identified that the children and their parents are younger; the type of activities the children prefer are different; many different languages are spoken by children and their families; and Indigenous people feel shy with strangers. Notably, Captains have needed to adjust their programs to suit a younger child audience and younger parents who are also likely to be entertained by the activities; children from remote and regional Northern Territory communities prefer 'hands-on' activities as opposed to computer based activities; the diversity of languages spoken by the children often means that Captains need to communicate without words utilising body language and visuals; and that it takes time to gain trust within a community.

The Captain Starlight activities conducted in the Northern Territory were reported to differ markedly from activities conducted elsewhere in Australia. Captain Starlight's work in the Northern Territory involves group activities with children attending the paediatric and healthy children's clinics in Alice Springs and Yirrkala and the spin-off activities conducted with the schools and child care centres. The high prevalence of

chronic disease faced by Aboriginal people necessitates a focus on keeping children healthy and supporting healthy living practices.

In hospitals, the Captain's work is similar to the 'traditional' Captain Starlight activities conducted with sick children in other states, although the activities in Northern Territory hospital settings tend to be more focused on one-to-one interactions between the children and Captain Starlight.

Higher levels of appreciation of Captains' visits were also noted by the Captains. The Captains understood this to be the result of the lack of alternative distractive therapies available to the children that contributed to the enhanced enjoyment of their program.

I think the biggest difference that I've noticed since I've been up here, is that the kids up here really appreciate our visits because they don't have all those other types of distractive therapies. Down south they have heaps of distractive therapies, music therapy, art therapy, and the clown doctors come in.

### **Recognition and acceptability**

The evaluation found that Captain Starlight was well recognised by staff, parents and children across all the sites visited on a regular basis. The Captain Starlight characters and their costumes are well received and are seen to be appropriate to the target group. Interviewees reported that the Captains are highly skilled, professional in their interactions, self sufficient and non-intrusive. The activities conducted by the Captains are fun and provide important play and health promotion input to children and communities that have little access to such entertainment.

In addition, the health service staff appreciate the willingness and flexibility of the Captain Starlight program to work outside of their core business area and provide support to community initiated activities.

### **Impact**

A number of impacts were identified by health staff responsible for children's clinics and wards.

#### **Improved attendance at clinic**

Fortnightly attendance at Yirrkala Healthy Kid's Club clinic by Captain Starlight is seen to encourage parents to bring their children to the clinics regularly. An observable impact on the children's health was noted.

[We see improvement] across the board like the children's monitoring of their HB's and just the anaemia problems and things like that are much less than when we started a couple of years ago because we do have this regular checking and interface with the people. ...all the mums know now that Wednesday morning is kids' morning and we're very precious about protecting it. We really do fiercely protect it because it has been the one thing that we can see we've actually made some progress on.

Yirrkala staff members reported that more children attend clinic on the days Captain Starlight visits. In Alice Springs, Congress staff were not able to link improved attendance with Captain Starlight visits because Congress provides a bus to collect children for their appointments and this is likely to have a significant impact on attendance.

#### **Impact of Captain Starlight as entertainment**

In both Alice Springs and Yirrkala, parents and children are staying longer at the clinics making it easier for health staff to manage the clinics with Captain Starlight's presence improving the environment at the health centres.

If the paediatricians are running a bit late which they can do, if the families are a bit bored with the whole thing, they might leave and if the Captains are around, they tend to hang around because you know, the kids are entertained, they're not wanting to be somewhere else. That's an impact that we tend to have—families that turn up for appointments stay for them (Paediatric Clinic Coordinator).

### **Impact of Captain Starlight sharing health promotion messages**

Many examples were provided on how Captain Starlight's involvement in health centre, school and child care health promotion programs has enhanced those programs.

... the Captains came back with these songs that they'd made up with little ukulele about 'We get measured, we get weighed' and all the rest of it—absolutely fantastic. And the thing was, when we did the Preschool screening, the kids were fighting over whose turn it was, and they were coming down the hallway singing what the Starlights had taught them. I can tell you that it had an effect.

### **Impact on the work of the health staff**

The running of clinics was made easier with the attendance of Captain Starlight. Health staff reported that Captain Starlight's visits do not require preparation and the Captains do not require supervision. With the attendance of the Captains, there is less concern about children and parents leaving before they have their appointments, with children tending to be more relaxed and less fearful when Captain Starlight is around.

If you look at how that affects staff...you know where the kids are, you know where their families are because they're usually at the front watching the Captains [and] that makes it easier to access them within the clinic.

The Captains' presence in the health centre and hospital was also reported to create a more welcoming environment and makes the centre feel less institutional and more family centred.

## **Suggestions for improvement**

The suggestions made for improving the Starlight Children's Foundation in the Northern Territory fell into two categories: suggestions for improving its effectiveness in specific settings and suggestions for expanding the program to enable other groups to benefit for the Captain Starlight entertainment and health promotion activities.

### **Improving the effectiveness of the Starlight Children's Foundation's current activities**

#### **Visit regularly**

The regularity or irregularity of the Captain Starlight visits presented as an important issue for the health centres and hospitals. Captain Starlight is most highly valued by the centres that they visit regularly. Regular visits enabled relationships to be formed and personal values attributed to joint projects e.g. art projects between the Captains and the children to be enhanced over a number of visits. Where visits were less regular, planning for a Captain visit by health staff was more difficult, recognition of the Captains was less apparent and opportunities to establish relationships with the children were limited.

#### **Advertise well in advance that Captain Starlight is coming**

Not all hospitals were clear about when Captain Starlight was coming to visit. Having a calendar of the Captains Starlight visits would assist health staff prepare for and make better use of the Captain visits. Knowing when the Captains would be visiting could also provide the children with something to look forward to and increase attendance on the day.

## Expansion of Captain Starlight activities

### Build the Captain Starlight Program into school, preschool and childcare health promotion programs

The value of tying Captain Starlight visits into health promotion activities was discussed by a number of childcare centre coordinators. Supporting the discussions was the very successful involvement of Captain Starlight in the Yirrkala school screening program where Captain Starlight's involvement had children jostling to have their immunisation shots, where normally they would be fearful.

In addition, the Yirrkala Childcare Centre Coordinator indicated that she is 'keen' to continue to work closely with the Health Centre to keep children up to date with their immunisations and to involve families in education sessions and activities about nutrition and keeping skin, ears, eyes and teeth healthy. Requests were made for Captain Starlight to work with staff on these sessions.

Congress child care staff are keen for Captain Starlight to visit regularly and include more health promotion songs that the children can learn from. Activities that focus on nose blowing, hand washing and good food messages were seen as particularly important.

I'm really keen to work with Captain Starlight...because I think that an external force coming in is very valid for children. Children seem to remember things too when other people tell them. So if we could build it up and encourage families to come and share the experience with the children. ...We could turn it into a bit of a family day and then, especially if they're doing health messages, it means that the families are getting the message as well and so hopefully with enough input, it will get right through (Childcare Centre Coordinator).

### Expand Captain Starlight visits to other Aboriginal organisations

Suggestions were made to expand the Captains program into other geographical areas and across a variety of childcare and screening programs aimed not only at supporting ill children but assisting with preventive measures.

I just think if they could expand the service it would be absolutely fantastic. Maybe they can't provide a regular service to everyone but one just to coincide with the screening and things like that. From a remote perspective trying to prevent disease instead of catching up later and trying to get people to think healthy [it is important]. We call this 'Healthy Kids morning', not sick kids morning or anything like that, it's called Healthy Kids Club; when we give out gifts it's welcome to the Healthy Kids Club, it is not about illness, it is about keeping your kids healthy and trying to prepare for chronic disease and things like that. So I think they're contributing to that certainly.

### Continue to support family days and Christmas activities

Also encouraged was the involvement of Captain Starlight in family days. The family day held by the Starlight Children's Foundation and Congress in 2006 was highly successful, attracting about 200 people.

### Increase the pool of Captains by training local people

The uniqueness of the Captain Starlight program was highlighted as was the lack of entertainment available to Aboriginal children from rural and remote communities. A number of people suggested the potential for training local Captains. Starlight is seriously considering the idea.

## Presenter

**Felicity McMahon** is currently the Head of Programs at Starlight Children's Foundation. Established in 1988, Starlight provides in-hospital and community-based positive distraction programs to children and young people who have a chronic health condition or serious illness. In 2007 Felicity joined Starlight to

undertake a needs analysis study that had a particular emphasis on the needs of children living in rural and remote Australia. The project involved consultation with over 300 families, health professionals and other experts from across Australia. The findings have guided the development of Starlight's long-term programs strategy, including the development of new programs in regional and remote Australia.

