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Deadly Threads: using creativity, culture and pyjamas to connect community to hospital

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Starlight Children's Foundation

For Indigenous children leaving their community in the Northern Territory for admission to hospital in Alice Springs, there are numerous challenges. In addition to the fear of medical procedures and the foreign environment of a hospital, feelings of isolation and disconnection to country are commonly reported as increasing the anxiety experienced by children and families. Amongst other initiatives, the Starlight Children's Foundation (Starlight) have been working with local partners on an Arts and Health project, "Deadly Threads", to assist in addressing this issue.

This paper will outline the history and delivery of this creative initiative. It will discuss key features of the "Deadly Threads" project, with a focus on the role of collaboration in ensuring the success of it. There will be a brief examination of the challenges that arose during the development of the project and how they were addressed. It will discuss whether intended outcomes, such as an increase in connection, cultural pride and individual confidence, were achieved and share any impact the project has had to date for the hospital community.

To provide context for the project, this paper will start by taking a broader look at the way the organisation works in regional communities, specifically discussing the "Healthier Futures Initiative" it delivers across the Northern Territory, South Australia, Queensland and Western Australia and providing examples of the impact of the program. It will also provide insight into Starlight's use of Arts and Health approaches for programming and how this platform underpins a number of initiatives in use with regional and Indigenous communities.

Starlight Children's Foundation

Starlight has been delivering programs, in partnership with health professionals, since 1988. The programs are designed to support the total care of children and young people who are living with a serious illness or chronic health condition. The focus is on providing "positive distraction" (including the use of performance, creativity and Arts and Health) to improve the healthcare experience of these children and their families.

Today, Starlight is the only children's charity with a permanent presence in every paediatric hospital, helping kids of all ages with any illness, injury or disability. In 2018, Starlight programs provided over 575,000 experiences to children, young people and their families across Australia and Starlight is now recognised as an integral part of the Australian healthcare system. All programs are based on the 'Charter on the Rights of Children and Young People in Healthcare Services in Australia', the

principles of family-centred practice, theories of child and adolescent development and Positive Psychology concepts.

Starlight's Healthier Futures initiative

Starlight launched its "Captain Starlight" program in 1991 and today there are over 160 Captain Starlights working in metropolitan, rural and remote hospitals and healthcare clinics. The program is delivered by professional performers from a wide range of backgrounds including actors, musicians, clowns and comedians. They engage with children and young people through activities such as art, music, story-telling, comedy and games to alleviate boredom, reduce anxiety and promote wellbeing.

In 2006, Starlight introduced the Captain Starlight program to remote Aboriginal and Torres Strait Islander communities. While Captain Starlight originally worked with seriously ill children in hospitals, Starlight's Healthier Futures Initiative broadened the impact of this vision. As early intervention is critical in preventing life-long chronic health conditions, regular health checks for Indigenous children are seen as vital. The organisation adopted a collaborative model, working to support health professionals as they undertake a range of interventions such as targeted heart and ear checks or more general screening programs. When mobile teams of health professionals visit regional and remote Indigenous communities, Captain Starlight accompanies them, utilising creativity, performance and principles of positive disruption to engage with children. The visits are undertaken in partnership with health professionals and are hosted by the Primary Health Care Centres or schools in the communities.

Captain Starlight now regularly visits remote communities in the Northern Territory, Western Australia and South Australia and has recently expanded into Queensland. In each location, Starlight collaborates with a key clinical service. For example, in Western Australia, Starlight has partnered with the Earbus Foundation of Western Australia (Earbus) for over 3 years. The focus of Earbus' work is Otitis media. This middle-ear disease has wide ranging negative effects on early childhood development, including the ability to learn and succeed in school and hence creating lifelong barriers that prevent children from achieving their full potential. Earbus mobile ear health clinics offer full primary health care to Aboriginal children in schools, day-cares, kindergartens and playgroups. Captain Starlights accompany the Earbus team on trip to the Goldfields, Pilbara and South West region and provide entertainment and positive distraction for the children who are attending the clinics.

A 2018 evaluation of the partnership found that Captain Starlights involvement reduced children's anxiety, assisted with the smooth and efficient running of the clinics, and created a more positive health care experience for children. It was also noted that the relationship and connections that formed between the Captains and the children extended beyond their regional communities. When children travelled for medical treatment to major urban hospitals (such as Perth Children's Hospital, Women's and Children's Hospital in Adelaide or Alice Springs Hospital), their familiarity with Starlight and the Captains tended to greatly reduce stress and anxiety in the unfamiliar hospital environment.

In 2018, Captain Starlight worked alongside health professionals to make clinic visits a more fun and positive experience for children living in over 90 remote Aboriginal and Torres Strait Islander communities in the Northern Territory, Western Australia, Queensland and South Australia.

Arts and Health

Many of the activities that Captain Starlights will employ on these trips to communities will have their basis in Arts and Health theory. Arts and Health (or Arts in Health) refers to the practice of applying arts initiatives in healthcare settings. It can involve any form of art, is suitable for people of all ages and abilities and can occur at any point in the healthcare journey. Arts and Health activities allow participants to experience the arts as an artist or creator, as a participant or member of the audience. Studies have shown that Arts and Health activities benefit a range of stakeholders including direct participants, artists who deliver the program, health service providers, and the wider community.¹

Arts and Health at Starlight

Starlight employs a dedicated Arts and Health consultant and through its Arts and Health initiative the organisation aims to:

- enhance the quality of holistic health care and the physical environment for patients and hospital staff
- build creative and cultural capital within the hospital
- foster a cohesive hospital community through creativity and artwork.

The following key principles underpin all Starlight Arts and Health projects. First, the project must fill a need or gap for patients and their families within the health care setting and creatively promote health and wellbeing. Second, projects should provide opportunities to patients and their families that they may not have had otherwise; Starlight's Art and Health initiatives turn the concept of "what do children and young people miss out on, because they are in hospital" to "what do they have the opportunity to do and experience while in hospital". Finally, Starlight is also committed to upholding the rights of the children in healthcare. The Charter on the Rights of Children and Young People in Healthcare Services² was developed in 2011 and applies to all children and young people receiving care in Australian healthcare settings. The Charter highlights that children and young people have a right to the highest attainable standard of healthcare and the consideration of their best interests as the primary concern of all involved in their care. They have a right to express their views; to be heard and taken seriously; to participate in decision-making and, as appropriate to their capabilities, to make decisions about their care; to be provided with information that is understandable to them; and have their privacy respected. Children and young people also have the right to participate in education, play, creative activities and recreation. As such, all Starlight initiatives aim to empower children and give them back a sense of control. Starlight asks children questions and listen to what they miss or would like to see while in hospital.

An evaluation of four Starlight Arts and Health projects conducted in 2016 identified multiple benefits for all stakeholders involved. Key findings included:

- Projects provided "positive disruption": All of the projects delivered elements of joy and distraction. Children were excited to having something new and different to do and be involved in an activity they would not normally have the opportunity to participate in inside the hospital;

¹ The Institute for Creative Health, The Australian National Arts & Health Framework, Retrieved March 12, from <https://www.instituteforcreativehealth.org.au/resources/australian-national-arts-health-framework>

² Charter on the Rights of Children and Young People in Healthcare Services in Australia, Retrieved March 12, from <http://www.awch.org.au/pdfs/Charter-Children-Young%20People-Healthcare-Au-version-FINAL-210911b-web.pdf>

- Expanded view of the hospital: These new and unique opportunities not only provided a fun activity but also gave children an expanded view of what is possible in hospital, especially the longer-term patients;
- Feeling valued: Children’s feeling of self-worth was boosted by having a professional artist choose to invest time in their ideas;
- Confidence, empowerment and self-expression: It was reported that involvement in these projects enhanced the children’ confidence. Additionally, self-exploration exercises for young people allowed them to identify and express what is important to them; and
- Chance to do something as a family: As the hospital focuses on the sick child and often siblings miss out, these projects provided an opportunity for the family to join in an activity.

A particularly relevant recent example of Starlight’s Arts and Health program is an “Artist in Residence” project. Every year, a large number of Indigenous children and young people are admitted to Perth Children’s Hospital (PCH) from all over Western Australia. Similar to children being admitted in Alice Springs as will be discussed in the “Deadly Threads” program below, Indigenous children in Western Australia face a range of challenges. The hospital is a foreign environment, and fear of medical procedures and feeling disconnected from their country and culture can heighten anxiety for these children and their families.

In 2018, as part of its first Reconciliation Action Plan, Starlight decide to design an Arts and Health project to bring Indigenous culture into the hospital and enable Aboriginal patients and their families to build cultural connections. Aboriginal and Torres Strait Islander artist, Jade Dolman, undertook a four-week residency in the Starlight Express Room at PCH. Ms Dolman is a proud Noongar artist passionate about sharing her culture. Over the four weeks, Ms Dolman worked on three large community canvas pieces relating to the elements of earth, water and sky. Both Indigenous children and non-Indigenous children and their families had the opportunity to create individual rock paintings. The painted rocks could either be taken home or back to the child’s room in the hospital. The rest of the rocks were used to form an art installation for the oncology ward. This art installation was led by Ms Dolman and incorporated elements of Noongar culture into the hospital.

The feedback about the residency was highly positive. It was reported that the project created familiar cultural points of contact for children in an otherwise foreign and frightening environment. The presence of culture made the hospital more comfortable, helped build cultural connections and last, but not least, provided Ms Dolmans with an opportunity to showcase her talent and work.

The “Deadly Threads” Project

At the same time the WA Artist in Residence program was underway, Starlight was also focussing on applying the same Arts in Health principles to address a similar issue in the Northern Territory. Numerous challenges were identified as facing the Indigenous children leaving their communities across the Territory for admission to hospital in Alice Springs. In addition to fear of medical procedures and the foreign environment of a hospital which every child experiences, often these admissions for Indigenous children are not planned. As well as being so far away from home, the suddenness of departure can exacerbate feelings of isolation and disconnection from country.

An additional challenge of the timing and lack of notice, is that many children are flown in from their community without their parents having time to pack what they need. Given the significant distances involved and limited transport, they cannot simply “duck home” to get whatever they may

have forgotten or had to leave without. These children, who often arrive without anything to wear during their stay, rely heavily on the plain royal blue pyjamas currently supplied by the hospitals. In the past, families have shared that the plainness of the pyjamas is not child friendly and the institutional appearance adds to their sense of displacement.

The concept

In 2016, Starlight Canada successfully launched its Wards + ROBES program. In Canadian hospitals, all children, upon admission are provided with standardised “robes” (or gowns) to wear while they are in hospital. Starlight Canada worked in collaboration with fashion designers across Canada to create a range of colourful, child-friendly designs for the ward robes. The designs were reported to give the paediatric patients wearing them a greater sense of individuality. Starlight Canada found that the project positively improved children’s mood and their sense of wellbeing.

Recognising the value in this, Starlight Australia considered how the concept could be adapted to our context. Starlight’s Arts and Health consultant closely collaborated with both Starlight Canada and Australian health professionals in regards to the idea. After learning more background detail from the Canadian initiative and the logistics involved, it became apparent that the model would have to be adapted for the Australian context. In Australia, very few children wear hospital issued gowns, however from Starlight’s work at Alice Springs Hospital (ASH) the team was aware of the challenges experienced by children and parents who face unplanned admissions and are spontaneously flown in from their remote home.

The Alice Springs Hospital Pyjama Pilot

After a potential need for the project had been identified, the Arts and Health consultant liaised extensively with Alice Springs Hospital at many of the crucial stages during the process to gain input, feedback and provide transparency about the design and logistics.

Key stakeholders in the process included children and families, the Aboriginal Liaison Officer and, perhaps unexpectedly, the hospital laundry department. The laundry department was crucial to involve as they maintain and distribute the pyjamas to children. In order for the project to be a success, the new pyjamas had to neatly fit into the existing hospital systems, that is they need to match the blue pyjamas that already exist at ASH, size and laundering ability needed to be coherent, and infection control protocols and Australian Clothing Standards needed to be adhered to.

The Aboriginal Liaison Officer was extensively consulted with regards to the design of the pyjamas. This consultation was important in identifying one of the key limitations of the project. There is a large number of unique Aboriginal communities in Central Australia, and it was important to design pyjamas in a way that was inclusive for all children (children from all Indigenous communities and non-Indigenous children). Hence, it was decided to use Starlight’s Healthier Futures indigenous brand and design as the basis for the pyjamas. The Healthier Futures design elements are the work of extensive indigenous consultation and artistic design and have previously been tested and shown to increase cultural content within Starlight’s programs and to acknowledge Starlight’s continuing work with Aboriginal and Torres Strait Islander people.

The Deadly Threads initiative was successfully launched at the beginning of 2019, in the Starlight Space at ASH. Feedback from families and health professionals at ASH about the new pyjamas has been highly positive. Many parents commented on the playful and child-friendly feel of the new designs. As well as an appreciation of the cultural awareness, one of the key themes has been the positive outcome of how to the families involved, their children “looked like children again” due to

their colourful design. There was also feedback about the positive sense of identity, and feeling less “institutionalised”.

At Starlight, impact and accountability is key, so all programs are underpinned by ongoing research and evaluation. Each individual program evaluation is tailored to the specific needs to the program it is aiming to evaluate. As such, a formative evaluation of the Deadly Threads program will be conducted later in 2019 and central to it will be the feedback of all stakeholders, including the children and their families.

The benefit of collaboration

In all the initiatives mentioned above (from the partnership with Earbus, to the Deadly Threads and the Artist in Residence project), close collaboration with key stakeholders was essential to the success of the projects. Starlight is deeply committed to working in partnership with other service providers and, in 2018, collaborated with 40 organisations on over 50 projects. Over the years, Starlight has noticed numerous benefits of collaborating with other organisations and service providers. These include:

- ability to designing programs that meet need by speaking to program participants and service providers on the ground
- partnering with organisations to combine and increase impact of individual programs, rather than potential doubling up on services
- enhancing the chances of program success due to extensive consultations on the ground with key stakeholders
- earlier identification and overcoming of barriers due to pooling of knowledge and expertise
- the ability to combine and increase impact of limited resources to achieve a common goal
- increased enhanced awareness of both organisations across different regions and sectors.

The future

Following on from the successful launch of the “Deadly Treads” pyjamas in Alice Springs, other hospitals have shown interest in the project and Starlight will work in close collaboration with them to ensure the pyjamas continue to fulfil a need and have a positive impact on children and their families. As part of Starlight’s ongoing commitment to Closing the Gap, Starlight is also investigating further opportunities to enhance wellbeing through the delivery of Arts and Health projects. Local partners and organisational collaboration will always be key to the planning and delivery of these projects.

Presenter

Dr Claire Treadgold is the National Manager of Research and Evaluation for Starlight Children’s Foundation. She has over twenty years’ experience in for-purpose organisations, with a particular focus on young people, health and community services. Claire was previously the General Manager of Operations and Services for CanTeen (the Australian Organisation for Young People Living with Cancer) and National Director of the YWCA’s breast cancer support program, Encore. With a PhD in Education, and other degrees in Arts, Communications and Youth Development, Claire has published papers on peer support, advocacy and service delivery amongst other areas.