

ROALD DAHL'S MARVELLOUS CHILDREN'S CHARITY

Marvellous Nurse Inventing Room Executive Summary

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**CHARITIES EVALUATION
SERVICES**

The Marvellous Nurse Inventing Room

The Marvellous Nurse Inventing Room funding programme was a three-year programme which funded twelve specialist nurse-led innovation projects that focused on finding new ways of supporting and caring for seriously ill children and young people. The funded projects produced innovative and engaging products and services; most of them were co-created with the involvement of children and young people using participatory methods. Products developed consisted of 2 animated films, 2 validated questionnaire and assessment tools, 1 short film, 1 suite of tablet apps, an information app, an art wall, a facebook group, a resource book, a patient document and one storybook and doll. The approaches used were new to most nurses leading the projects and were for the purpose of supporting and providing information, improving patient experiences and finally providing creative therapy. The experiences were both educational and enjoyable for participants and staff.

RDMCC commissioned NCVO Charities Evaluation Services (NCVO CES) to evaluate the MNIR programme both in terms of programme outcomes and project delivery and to include recommendations for RDMCC on further learning dissemination and development of future funding programmes.

The evaluation investigated the following questions

- What difference has the MNIR made for children and young people and their families?
- What difference has the MNIR made for nurses, their services and their organisations?
- What services or products have been created?
- What new learning has been generated?
- What opportunities are there for RDMCC to use the MNIR outputs, outcomes or learning to create further positive change for seriously ill children and young people?

Key Findings

The possibility to improve healthcare more broadly

The funded projects all have elements that have potential to be transferred to a wide range of settings, conditions and patient groups, including beyond the conditions for which they were originally developed. There is potential for the work of the funded projects to improve services and patient experiences across healthcare services throughout the UK, particularly those caring for seriously ill children. There is scope for Roald Dahl's Marvellous Children's Charity (RDMCC) to help facilitate this through advising funded organisations, encouraging partnership working and utilising its own networks, connections and influence.

Children and young people given a voice

Seriously ill children and young people have been given a voice and an opportunity to improve the services that they use. Through taking part and coming together with other families in workshops, focus groups and events, project leaders reported that young people and their families have improved their abilities to cope, found new sources of support and in some cases improved their family relationships.

Nurses have learnt new skills

Nurses have learnt new skills in leadership and project management and enhanced their child-centred approach through the use of participatory research methods and approaches. Funding similar nurse-led projects would give RDMCC the chance to develop the skill sets of funded nurses which could give them career progression opportunities, as well as benefiting more young people.

Creative and innovative products and services

This was the key and core aim of the projects in the programme and was successfully achieved in them all. Through the development of new innovations, services have been or have the potential to be, improved. The use of technology and artistic activities in the everyday care of ill children and young people has the potential to improve their health and well-being. A number of arts and technology products were created: short films to tell the experiences of life with a long-term or serious condition; resources to increase children and young people's knowledge and improve their resilience and happiness; and new validated questionnaires to help services capture patient experiences more accurately.

The value of a family-centred and holistic approach

Evaluation of the programme found that a family-centred approach to care is valuable, acknowledging that each member of the family of a child or young person with a long-term condition has an effect on the happiness and well-being of the others. Attending to the holistic needs of a child or young person with a long-term condition also proved important; considering their social, emotional and clinical needs ensures ill children are not only defined by their condition. In using family-centred and holistic approaches, nurses learnt that different ways of engaging with children and young people can result in different forms of interaction; formal and informal interactions and place and setting can all have an effect.

Summary of recommendations

The recommendations in this report are intended for consideration by RDMCC regarding the future funding of programmes. They aim to ensure funded projects achieve their outcomes and improve the abilities of the nurses that lead them, and in doing so make sure children and young people play an active and meaningful part in the development of their healthcare services. This section collates all recommendations provided throughout the report.

Project planning

- Do even more than in this programme to provide guidance to applicants to help them learn the lessons from these projects and those in the original programme. In particular:
- Ensure funded projects consider the feasibility of project plans and identify **barriers and potential risks to success**. At the application planning stage, they should show they have obtained the specific agreement of other internal departments crucial to the success of the project, including any needed for proposed dissemination plans. Consider requiring all applications to have a senior level project sponsor to assist this by helping them navigate the organisational systems, and strengthen the buy-in of the wider Trust.
- Strengthen further the arrangements to ensure that the **skills** needed to run a successful project are available or covered in workshops and bespoke expert support. We suggest asking successful applicants to complete a **skills** self-assessment for the team, including planning, budgeting, project management, communication and leadership. Consider providing compulsory project management training for those below a certain skill level. Cover communication skills in the RDMCC workshops.
- Require applicants to specify the **time** required for the project by them and other staff involved, and to describe arrangements for additional resource/backfilling, to avoid nurses attempting to do their normal job plus the project work within their standard working hours.
- Require in the application a preliminary **dissemination** plan.

Project delivery

- Recognising the social model of care, future funded projects should be designed with the whole families' needs and involvement in mind.
- Encourage projects to consider the place and settings of planned activities and how intended participants may feel about them because different settings may illicit different responses.
- Application guidance should include advice on partnering with organisations for delivery and dissemination.

Research methods

- Encourage involving children and young people in the design of services and as co-researchers.
- Provide guidance on good practice and issues to consider when using participatory research approaches.
- Provide guidance on potential challenges and resource issues that may arise from involving seriously ill children in participatory research.

Sharing learning

- RDMCC to encourage funded projects to produce practical guides to replicating projects as well as traditional journal articles.
- Investigate the feasibility of funded projects publishing information about their projects on online open-access platforms relevant to nurses including RDMCC resources.
- Encourage the use of social media and the internet by funded projects to share learning. Consider providing guidance and/or training for how to use social media and the internet to share learning.

Product development

- The intellectual property rights of products and services developed with grant funding should be made clear in funding guidelines and funding agreements.
- RDMCC to consider and identify which products have potential to be used across NHS Trusts and communicate their availability and the possibility of purchase.

Peer support

- Encourage projects that facilitate peer support for parents and families, either face-to-face or via any form of electronic communication.
- Promote peer-to-peer interaction and support for children and young people
- Promote and encourage mechanisms for sharing learning among Roald Dahl nurses on a regular basis.

Transferability

- RDMCC to consider how they can encourage the take-up of the project products by other relevant services. This may be by selecting one or two products as priorities for transferability, and/or by focussing on particular specialisms or patient groups, possibly those where RDMCC have the most expertise or links.

Funding programmes

- Require all funded projects to participate in an evaluation diagnostic meeting with an external expert to ensure project leads have the skills to effectively evaluate their project and provide RDMCC with good quality final reports.
- Consider prioritising projects led by Roald Dahl nurses so that the programme can focus on enhancing the skills development of nurse leaders along with the enhancement of other knowledge and skills.
- Ensure that any RDMCC programme either recruits project leads with the requisite team working or collaborative working skills or that the programme itself covers these skills ensuring that applicant guidance includes consideration of these issues in the planning of projects.

About NCVO Charities Evaluation Services

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- external evaluations
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