



An
evaluation
of the
wellChild
Children's
Nurse
programme

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Executive Summary

Introduction

WellChild, the national charity for sick children, developed the WellChild Children's Nurses Programme in 2006. The aim of this programme is to ensure that children with complex health care needs can be cared for within their own homes, whenever possible, whilst their families receive appropriate support to maintain a sense of family life. This aims builds on and fits well with recent Government initiatives and the campaign 'Better at Home'.





Central to the programme are the WellChild Children's Nurses who work with children with disabilities, long-term ventilation needs, and complex health care needs. Their roles are diverse, responding to local need, and developing as their role becomes more firmly embedded within their individual settings. At the time of the study there were nine WellChild Nurses posts supported by the charity.

This study, commissioned by WellChild, reports an independent evaluation of this programme which aimed to explore and evaluate the roles and impact of the WellChild Nurses and to help inform the future strategic direction taken by WellChild in relation to this programme.

Methodology and Methods

An affirmative, participatory research methodology was adopted to encourage and facilitate involvement and engagement with a range of participants across each of the nine geographical settings.

The following methods were utilised:

-  Interviews were conducted with the WellChild Nurses, stakeholders working with the WellChild Nurses and strategic stakeholders.
-  Children and their families whose care had been provided/directly influenced by a WellChild Nurse were invited to share their views through the use of Photo-Voice diaries.
-  A Training Needs Analysis Survey (TNAS) was developed and used to explore the WellChild Nurses' self assessed priorities for training, education and professional development.
-  Caseload and documentary analysis of reports, job descriptions, and other material was undertaken to provide contextual and activity data.

Ethics approval was sought and gained prior to commencing the study. Throughout the study ethical principles and good research practice were adhered to and research governance attended to. Information about the study was circulated and care taken to ensure that no-one felt pressured to participate. Consent and assent (as appropriate) were gained from all participants.

Data Analysis

Analysis of the data was undertaken by the team members using a reflexive, collaborative and iterative process. This resulted in themes being identified from the qualitative data, from which three main domains which reflected the core meanings were established. Descriptive statistics were used to analyse and report on the quantitative data.

Findings

Recruitment occurred from all nine settings in which WellChild Nurses were working at the time of the study. The participants comprised of past and present WellChild Nurses (n=9); stakeholders from the WellChild Nurse settings (n=37) who represented people working in acute and community health, education and social care settings; strategic stakeholders (n=5); and children and their families (n=2). It should be noted that 14 families wanted to participate in the study. However, despite their willingness to contribute the competing demands in their lives, such as changes to their child's health, meant that 12 families could not find the time to complete the diaries.

Overall it was evident that the WellChild Nurses were perceived positively by the stakeholders, children and families who engaged in the evaluation. The WellChild Nurses had successfully impacted on the care of children and their families in relation to timely discharge, co-ordinated care and increased inter-professional working across health, social care and education. The WellChild Nurses' abilities in establishing, developing and sustaining services and networks flourished over the period of time they were in post.

Three core domains were identified that reflected the journey taken by WellChild as well as the journeys taken by each of the WellChild Nurses within their individual roles. These three core domains were embarking, embedding and sustaining.

a) Embarking

This domain examines the beginnings of the WellChild Nurse Programme, how it developed and its early implementation. It provides analysis of the processes underpinning the way that organisations applied to WellChild for funding for a WellChild Nurse as well as the application process and personal specifications for nurses applying for a WellChild post.

It also maps the journeys taken by the WellChild Nurses as they settled into their new roles, developed a 'sense of belonging', worked with other stakeholders and navigated the complexities of organisational structures. The WellChild Nurses were having to forge new roles across organisations and agencies and their initial months were spent familiarising themselves with the settings and people, establishing networks, and explaining and developing their roles. For those whose roles included a caseload, these early months were also spent getting to know the families and identifying the actions that needed to be taken.

Embarking is also a period in which the WellChild Nurses accustom themselves to working with and for a charity. Being charitably funded created some tensions in the WellChild Nurses' everyday working practice, particularly in relation to sharing information about the children and families to whom they were providing direct or indirect care.

b) Embedding

Embedding is the domain addresses the ways in which the WellChild Nurses make changes within practice and create bonds between individuals, organisations and agencies to improve the care of children and their families.

The WellChild Nurses were seen as a form of 'organisational glue', holding together disparate agencies and professionals, acting as a resource and thus ensuring a coherent and cohesive approach to caring for children and their families. Making even seemingly simple changes - such as the implementation of a discharge board within an organisation - often reaped substantial rewards in terms of enhancing discharge planning.

The success of the role was contingent on the knowledge, skills, and expertise of the nurses, who were able to draw on excellent inter-personal skills, a genuine sense of commitment and a high level of professionalism to bring about change. This expertise was linked with

an eagerness to extend their own knowledge and skill as well as to develop the knowledge, confidence, competence and skills of the families and professionals they worked alongside. A more flexible approach to fulfilling the training needs of the WellChild Nurses is presented and discussed.

This domain also examines the ways that the charity has developed its processes as it has learned to enhance its working practices.

c) sustaining

Sustaining examines the conditions in which a WellChild Nurse can flourish.

In this domain the relative merits of the WellChild Nurse working within either an in-reach or out-reach service model are discussed. However, what appeared to be crucial to the success and potential sustainability was the commitment to and management of the role within the organisation.

The pay banding across the nine posts ranged from Band 6 to Band 8 with little obvious difference with scale, scope and nature of the jobs themselves.

Key to the sustainability of both the WellChild Nurses Programme and the changes made within individual settings is the need for a review of the reporting mechanisms and the means by which changes are documented and data collected. More robust methods of sharing ideas and disseminating practice are suggested as a means by which the work of the WellChild Nurses and WellChild can be more influential.

External mentorship of each WellChild Nurse and closer links between the WellChild Nurse and their local Higher Education Institution could provide direct support to the development of practice and research.

Overview of recommendations

In order to help shape the future direction of the WellChild Nurses Programme, key recommendations were identified. The thirty recommendations presented can be briefly categorised into the following key areas:

1. Reports and documentation

Recommendations in this section related to the need to further support WellChild Nurses by developing and ensuring consistent, transparent and robust partnerships between WellChild and the host organisations. Robust processes should exist to cover application, induction, ongoing management of the role, evaluation of outputs and changes, and the strategic planning for sustainability of the role and role succession. Clearer reporting mechanisms would allow tracking of individual roles against the initial aims and objectives. Additionally better reporting mechanisms are needed to help to generate a central dataset that would allow more robust analysis of the effectiveness of the posts and programme.

2. tensions associated with charity funding

Recommendations in this section related to the need for WellChild (and potentially other children's charities) to consider the tensions inherent in charitably funded roles where children's nurses and their host institutions have to manage the competing demands of ensuring they work within their Code of Conduct whilst assisting the charity with publicity.

3. Supporting the WellChild nurses

Recommendations in this section related to the need to provide individualised and tailored mentorship and educational opportunities for the WellChild Nurses that help to bridge professional and academic boundaries including opportunities to contribute at a




national level to the development of complex care. In particular, WellChild should consider establishing an Academy of Children's Nurses that could act as a resource to support the leadership, research, clinical and academic development of the WellChild Nurses and the field of caring for children with complex health care needs.

4. Knowledge transfer & dissemination

Recommendations in this section related to the need to enhance the opportunities for sharing the knowledge and skills of the WellChild Nurses through a central repository of ideas and documentation which could promote knowledge transfer at a national (and potentially international) level.

Further research

Clearly WellChild, the WellChild Nurses and those who have assisted the Programme have contributed to the further development of improved discharge planning for children and their families. This warrants closer scrutiny through a programmatic approach to research; the following examples provide illustrations of the areas and potential methodological approaches that could underpin a programmatic approach to research in this area.

-  A longitudinal study that continues to track the work of the WellChild Nurses to examine the outcomes and impact of the role
-  Ethnographic work with families that would allow the researchers to develop a genuine sense of the difference that the WellChild Nurses can make to family life.
-  In-depth case study work of selected in-reach and out-reach settings over a longer period of time, which could provide a more detailed examination of the particular merits and disadvantages of each approach.

Conclusions

This study explored and evaluated the WellChild Children's Nurse Programme. Each role is different and each of the WellChild Nurses has faced different challenges and has worked strategically and clinically to bring about change. The WellChild Nurses represent an exceptional set of individual practitioners whose experience, expertise, ability to establish relationships and to attract commitment from other professional is evident from the outcomes they have achieved.

The working relationship between the WellChild Nurses and WellChild has generally been extremely positive with the WellChild Nurses benefiting enormously from the particular positioning within the NHS that a charity funded role provides. The tensions relating to 'publicity' have been and continue to be addressed as this is likely to continue to be a somewhat contentious issue for WellChild Nurses, particularly during their first months in post as they adjust to the role.

Just as each role is different, so is each setting. The stakeholder feedback has largely been very positive, describing the ways in which the WellChild Nurses enable change and help to develop other people's practice. Settings which provide a supportive context in which the WellChild Nurse can work, gain the most in terms of positive outcomes. The role is important not just to the individual families helped but also in terms of its potential contribution to a national understanding of how to best support children, families and other stakeholders.

One of the families reflecting on the positive changes resulting from contact with 'their' WellChild Nurse summed up their feeling by advising other families that:

"If you don't have a wellchild nurse then ask for one".

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