Training community nurses on supporting families with children who have developmental difficulties. Lessons from the former Yugoslavian Republic of Macedonia.

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Abstract

Purpose: In the former Yugoslavian republics, community nursing services are not well developed to support families with infants who have developmental problems. The aim of this study was to develop an in-service training package for nurses on supporting families of children with developmental disabilities. **Method:** A conceptual framework guided the design and content of the training package which was further consulted on with local partners. A cascade model of training was adopted, based largely on experiential learning. A nine session training package (around 20 hours in all) was devised and a Training for Trainers workshop held to prepare them to use the package in their locality. The inservice training of nurses is ongoing during 2014-15. **Findings:** Key findings are presented in relation to perceived training needs; the key features of the Training Framework; the content and teaching methods used and the outcomes of the Training for Trainers workshop. Ongoing evaluations during 2014-2015 will assess the impact of the training on community nurses and on families. **Originality:** This study provides a conceptual model for the provision of effective inservice training on developmental disabilities for community personnel throughout the region and internationally.

**Key words:** Developmental disabilities; parent education, antenatal care; community nurses, in-service training.
Introduction

International estimates suggest that over 20% of children in low and middle income countries (LMIC) are likely to have developmental problems (UNICEF, 2008). Most will experience mild difficulties but even so their educational progress is liable to be affected. A smaller proportion – between 2% and 5% - will have marked difficulties that will require life-long assistance.

Longitudinal research suggests that the influence of families on a child’s development outweighs that of formal systems such as schooling (Shonoff and Phillips, 2000). Moreover parents can be effective teachers and therapists of children with disabilities when they are provided with relevant information and guidance (Roberts and Kaiser, 2011). Home-based support from the child’s birth onwards has proved most effective in promoting the child’s development as well as helping mothers in particular to adjust to the emotional demands many experience (Kendall et al, 2000; Nievar et al., 2010).

A major challenge in low and middle income countries is the relative a lack of expertise to support parents (Engle et al., 2011). There is a scarcity of trained professionals who have the knowledge or skills in early childhood intervention and family support. Specialists such as therapists, special educators and psychologists can be in short supply and given the economic constraints of these countries, it will some years before they can expect to match the range of services available in more affluent countries. In these circumstances, the only viable alternative is to look to existing staff in hospital-based or community services to offer the necessary support to children and families. In many countries the most promising option is community health workers who are present in some form or other in nearly all countries globally (Lewin et al., 2006).

An international imperative of late has been the promotion of Children’s Rights. UNICEF has been to the fore within the Eastern European region in promoting early childhood intervention and in particular, the contribution that community personnel could make to achieving better outcomes for children at risk of developmental difficulties or who have a developmental disability, especially a reduction in institutionalization rates and access to education (UNICEF, 2012). The present study describes the conceptual framework that was developed to realize this aim with particular reference to the in-service training of community nurses.

The Country Context,
The former Yugoslavian Republic of Macedonia is a land-locked country of around two million persons surrounded by Bulgaria, Albania, Greece and Serbia. In common with neighbouring states it has experienced societal and economic problems arising from inter-ethnic conflicts and the transition from a planned to market economy with high levels of poverty, unemployment and marginalization of vulnerable groups. Macedonian and Albania are the two dominant languages.

In the former Yugoslavia, patronage nursing services were deployed in their local communities in a similar way to public health nurses or health visitors in other European countries. This included health promotion and illness prevention activities within the community, such as immunisation programmes for children, as well providing nursing care and treatment interventions in a non-hospital settings and acting as community midwives in providing support to women and their families during pregnancy, delivery and postnatally. In some instances they also provided care and treatment to those with mental health problems and learning disabilities in their home environment, including crisis intervention measures (World Health Organisation, 2005).

However the nurses received little additional training for these roles which were perceived as low status in comparison to hospital –based nurses (Curatio Consulting, 2011). They had minimal contact with families whose child had a disability; most were referred to doctors and defectologists based in the capital city. Many children were institutionalized (Velichkovski and Chichevalieva, 2010).

**Project Aims**

UNICEF Macedonia commissioned the project following on from a broader review of patronage nursing services with the country (Curatio Consulting, 2011). The overall aim of the project was to enable and empower patronage nurses to change their practices to offer better support to families whose children have developmental difficulties. The following are examples of the new tasks and roles nurses could offer within their communities based on international experience and the local needs assessments undertaken at the commencement of the project (see later).

- Detecting infants and preschool children for potential developmental difficulties and referring them for assessment;
- Educating families about developmental disabilities and teaching activities to promote the child’s development;
• Making regular home visits to families at risk to monitor children’s progress and assess family situation;
• Communicating with other services to whom the child and family have been referred;
• Providing emotional support to mothers especially and encouraging them to develop informal support for themselves; and to advocate for their needs;
• Nurses with specific expertise in caring for families with children who have a disability can act as a resource to other nurses in their health centres who have not been trained.

The provision of a training course on developmental difficulties to existing community nurses was seen as essential to achieving the reformed role for nurses. Two conditions were considered fundamental. First, the training should be owned and delivered by the managers of nursing services so that their commitment to the new functions of their staff was assured. Second the training should be available within localities and be easily repeated as new staff join the nursing service. Both of these requirements were fulfilled by creating a package of training resources for use by local trainers. At a later stage the package could be used within preservice nurse training either as a core or elective module.

Moreover the training approach and content should be transferable to other countries in the region and was seen by UNICEF as one part of a regional strategy for Central and Eastern Europe and the Commonwealth of Independent States to support the wider development of community nursing services (UNICEF, 2011).

Hence the main output from the project was to produce a high quality, effective training package on developmental disabilities which can be used by nurse educators in both in-service and pre-service training courses in Macedonia. In addition this study would also provide a test of a conceptual framework that could guide the development of further training courses within the region and internationally for other community personnel – such as teachers, preschool personnel, midwives and doctors - on the topic of developmental disabilities.

**The conceptual framework.**
Figure 1 summarises the main elements of the conceptual framework that evolved during the project. The overall outcome of changed nursing practice was a constant point of reference for all elements within the framework. Although the four phases are presented in a discrete linear fashion, in reality they formed an iterative process across the four phases.

*Insert Figure 1 about here*

**Phase 1: Evidence gathering**

Although the international consultants recruited for the project had expertise in nurse education, midwifery, public health and developmental disabilities, a priority for them was to understand the local situation and gain insights into the stakeholders’ insights into how the aims of the project could be attained. Despite access to fluent interpreters with past experience of nursing services, translation to/from English to Macedonian slowed the process considerably.

Meetings or interviews were arranged with the following:

- Ten parents of children with developmental disabilities recruited from three organisations and centres;
- 34 Patronage nurses and managers plus three nurse educators from different regions of Macedonia;
- The president and executive committee of the Macedonian Association of Nurses and Midwives (MANM);
- Three colleagues from UNICEF Macedonia on the related early childhood initiatives that were ongoing in the country and region;
- Eight directors of relevant government departments and institutes relating to child development.

These local insights were complemented with a review of international knowledge and experience in the following areas: support for families and promoting the development of children with developmental disabilities; the development and delivery of education for community nurses; and the provision of training on developmental disabilities to non-specialist community personnel.

The outcomes from these consultations and reviews were collated into an assessment of training needs within Macedonia that was circulated among the above informants (Sinclair
et al., 2013). Proposals for the design of the Training Framework were derived from these analyses.

Phase 2: Design

Values

The main values that should underpin the training framework were identified at the outset and confirmed during its development. They were:

Partnerships: This was epitomized by the partnership between local agencies in Macedonia and the international consultants. However this extended also to the relationship that nurses would have with families as well as with other service agencies who can support families.

Family-centred: The well-being of the family as well as the child must be the focus for Patronage nurses within a holistic approach to care. Hence the personal needs of parents should inform both the training package as well as the supports provided by Patronage nurses.

Valuing every child: The attitudes and perceptions of professionals and parents are shaped by the stigma associated with disability. These need to be challenged and changed if the rights of children are to be upheld. Effective techniques for reforming attitudes need to be an integral part of the training framework.

Socially Inclusive: The discrimination and isolation experienced by children with disabilities needs to be replaced by their social inclusion within society; starting with families and extending into local communities and ultimately national systems. Thus the first response is for the needs of families and children to be met within existing community services. Indeed for most families in low and middle-income countries, these will be the only forms of support commonly available to them.

Culturally sensitive: The training package needs to be sensitive to national practices and policies as well as to cultural responses to parenting, child development and disability. Training interventions developed in other cultures cannot be transported into other settings without checking for their suitability. Moreover cultural applicability applies to sub-cultures within nation states including immigrant communities.
Learners

The training package had to be designed to meet the particular needs of the learners; that is practicing nurses, many of whom would have had many years of experience. It was vital to recognize the assets they could bring to the training and the intended outcomes; such as their familiarity with local cultures and perceptions about disabilities; their knowledge and skills in promoting the child’s health and preventative actions such as immunisations, good antenatal and postnatal care, and the services available locally and nationally to assist children with developmental difficulties and their families.

The amount of time they could be released from their daily duties to undertake training was limited - around 20 hours in total was proposed. Thus in our consultations we had to identify priority training needs which were then translated into the objectives of the training package.

Objectives

The chosen objectives for the training proposed and agreed in another round of consultations were:

• To ensure nurses appreciate all children’s potential to learn and to develop, and the vital contribution that parents make to this;
• To increase nurses’ knowledge of child development and its various domains – physical, social, cognitive and emotional development;
• To enable nurses’ to detect children for possible developmental difficulties or at risk of acquiring them, and to make appropriate referrals;
• To provide parents with accurate information on developmental difficulties and challenge myths and stereotypes;
• To guide parents to use strategies to promote the child’s development and well-being;
• To offer empathic emotional support to parents as well as the provision of high quality pre-natal and ante-natal care to mothers;
• To signpost parents to health and social services within their locality;
• To liaise with clinicians, local services and agencies to encourage them to provide families with the necessary supports; and
• To prepare nurses to maintain records of family needs and outcomes achieved.
Trainers

The package was designed to be delivered by local personnel. Again our consultations helped to identify the likely attributes of effective trainers.

- They have successfully worked as a Patronage nurse;
- They hold a managerial position within the service and can influence the development of the service;
- They are respected by their colleagues and have the necessary personal qualities to be a trainer: e.g. empathetic, supportive, good communicator.
- They have experience of training and mentoring.

There could be some advantages for trainers from one locality to train personnel in a different locality. This would encourage exchanges of good practice.

The trainers needed to be released from their usual duties to attend the training for trainers workshop and subsequently to undertake training courses in their own or other localities. These represented additions to their current role and workload albeit they can be introduced on a gradual basis.

When the package was used in pre-service training, the trainers would come from the existing college staff but ideally they too would have some of the above characteristics.

Phase 3: Content

Once the broad design of the training package had been identified and agreed, detailed planning of the content commenced.

Learning Outcomes

Training can produce three types of learning outcomes. Firstly, the students acquire new knowledge, information and understandings by the. Secondly, the development of new skills, competences and ways of working as the new knowledge is applied by nurses in their work with children and families. But the third component is arguably the most crucial: training needs to nurture new attitudes, challenge stereotypical beliefs and inculcate the values required by nurses to fulfill their job role. Our consultations indicate that this aspect needed particular emphasis in this training package; hence the focus on experiential learning methods.
**Teaching Methods**

Adult learners tend to favour problem based learning and to draw on their reservoir of previous knowledge and experience in approaching new learning, and to they prefer to direct their own learning (Knowles, 1980). Thus the package consists of a variety of teaching and learning methods with a focus on experiential learning to change attitudes, to nurture new skills and for gaining new knowledge. Students take part in activities such as role playing, working through scenarios or problem solving exercises that are followed by critical reflective activities. Reflection aids the student in re-forming their attitudes; gives a greater understanding of new knowledge but primes students to assess their own practice (Johns, 2009). These approaches are likely to be novel for trainers as well as students which was a further rationale for the need to provide training for the trainers.

**Modules**

The course content reflects the objectives of the package and is divided into nine, self-contained modules. The Trainer’s guide provides detailed lesson notes for each module that would last around two hours. These follow a common structure. An overview is given of the learning outcomes anticipated in terms of the acquisition of student knowledge and understanding; the skills they will be encouraged to acquire and the changes anticipated in their attitudes and perceptions. The nine modules are shown in Table 1.

*Insert Table 1 about here*

The intention is that particular modules or groupings of modules can form a discrete training event thereby providing flexibility to suit the needs of different learners. Thus a single module could be presented in a ‘one-off’ event or a group of modules could be presented within a one or two day training event or the entire package could be taken over nine sessions, one per week over a period of time. This flexibility is necessary if the package is to be used in both in-service and pre-service training.

The modules are seen as providing an introduction to each topic. In due course, further modules at different academic levels may be added to create more advanced training opportunities for nurses as their role evolves. Such training would be especially necessary if the model of specialist nurses was to be adopted within the wider community nursing services.
Resources
The package utilizes modern information technology to ensure students receive a high quality learning experience on par with that available internationally. The content of each module is covered in a specially prepared Powerpoint presentation that describes recommended teaching methods. In addition, student handouts are provided along with other resources needed for the lesson, such as video illustrations. Additional resource materials are included in the Trainer’s Guide usually as downloads from the Internet.

- **Powerpoint presentations**: These summarise the main points of the lessons along with photographs and diagrams. The trainer’s notes are embedded within the Powerpoint presentation to guide them on the learning activities they can use with the students.
- **Video extracts**: These include interviews with mothers of children with developmental disabilities; with patronage nurses working in Macedonia along with selected videos from You Tube.
- **Learning Activities**: A variety of activities are included in each module for students to undertake during the session usually in pairs or small groups. These are designed to ensure students engage with the topic and become active learners. It is also an opportunity for them to practice important skills, for instance when they take part in role plays.
- **Student Handbook**: This contains a copy of the slides in each presentation. Students can make additional notes on these pages. Also included are handouts for use with students in learning activities or which they can use in their work with children and families. This Handbook can be used as a reference resource after the training.
- **Further reading and resources**: References are given for further reading and useful Internet websites that trainers and students can access. Unfortunately these are mostly in English but as the training is rolled out in Macedonia, trainers are encouraged to develop a repository of translated resources.

The Training Package consisting of the above resources is available from the Macedonian Association of Nurses and Midwives with UNICEF Macedonia covering the initial production costs. The trainers mostly had access to suitable training rooms and the necessary equipment. Nearly all had access to the Internet.
Phase 4: Delivery

Training for trainers

A ‘Training for Trainers’ workshop was delivered and evaluated as part of the development of the Training Package. This proved a valuable experience and new trainers should have the opportunity of participating in a similar event. The main aims of the workshops were:

- To model for the participants, the experiential teaching and learning approaches which are the core of the package.
- To highlight particular attributes of trainers and the techniques they can use in their training sessions.
- To boost their confidence and competence as trainers.
- To draw upon their experiences as nurses in local communities to revise and refine the training materials.

The workshop programme had a number of key features:

- Each participant had the experience of presenting one module from the training package to their colleagues who played the role of students. To facilitate this, the 19 trainers were divided in three groups for these presentations.
- After each presentation by a trainer, the group reflected on aspects that had worked well and suggestions for improvements.
- Each day started with three short presentations from the international facilitators on themes relating to training.
- On two days, the sessions ended with a plenary session in which presentations were given by parents of children with disabilities and by doctors working in the health system with these children.
- The trainers were introduced to the concept of ‘ice-breakers’/warm-up activities as a means of relaxing participants and conveying the message that the workshop would emphasise experiential learning approaches.
- The importance of evaluating the training was stressed throughout all presentations and means for doing this were presented and used.

The workshop also provided an opportunity for trainers to plan local training courses and to pilot the evaluation questionnaires (see below).
Selection of Patronage Nurses for training

Consideration needs to be given at a local or regional level as to which nurses are selected for in-service training. Among the personal qualities that were identified in our consultations were the following: they are motivated to help families and children; they are seeking to improve themselves and the service they provide; they are willing to try new approaches; they are confident and assured, inspiring trust from others; and willing to seek advice from others and to share with others.

These qualities could be used as a guide when prioritizing students for training although other factors may also be need to be considered such as their motivation to study, leadership potential and personal commitments that may create difficulties in attending for training.

Action Planning

Arguably the most critical part of the training framework is its implementation by local personnel. In order to encourage this, the following actions were taken.

In the final session of the Training for Trainers workshop, the trainers planned the delivery of the courses for the remainder of 2014. Three regional training sessions would be organised initially - in Skopje, in the eastern region and in the western region - with a small team of trainers presenting the training in each.

UNICEF would support the Macedonian Association of Nurses and Midwifes in co-ordinating the courses; the distribution of resources and in collecting attendance and evaluation records.

The Ministry of Health is undertaking a review of patronage nursing services in Macedonia and it is anticipated that an expansion of inservice training will be recommended.

Evaluation

Two types of self-completion questionnaires are included in the package so that trainers can assess its impact. These were first piloted with the 19 trainers at their workshop. The first elicits students’ reactions to the training course using a mix of rating scales as well as open questions. Overall 79% (N=15) of trainers rated their workshop as being ‘very useful; and a further 21% (N=4) as ‘quite useful’. None were recorded as ‘no or little use’. Moreover 53% rated their personal teaching experience using the materials as excellent and a further 47% as good. In all 55% rated as excellent the preparation they had been
given for presenting local courses and 45% as good. No one recorded the training as satisfactory or poor.

Among the responses given when asked the most enjoyable part of the course were: “Group work; interactive approach; the play for children; teamwork; when I was teaching the module; all presentations and activities; exchange of experiences and ideas; respecting of differences, detection of disabilities.”

The second questionnaire contained items relating to students’ knowledge of developmental disabilities, their attitudes to children and people with disabilities and their feelings of comfortableness in meeting people with disabilities. Trainers were invited to complete this questionnaire by rating each item on a four point scale prior to the start of the workshop and again at the final session. It took around 10 minutes to complete.

The trainers rated their knowledge of disability significantly higher after the workshop (the mean score rose from 57 [range 43 to 73] to 84 [range 70 to 96]; T=10.4: p<0.001). Their feelings of discomfort when with disabled people also decreased (from a mean of 21 [range 16 to 26] to 16 [range 8 to 21]: T=2.22; p<0.06).

Of course, the impact of the training package on the nurses’ practice - in both the short and long term - remains to be formally evaluated along with the reaction of parents and families with whom they had contact. This would constitute a valuable research and development project that would not only yield valuable data in its own right but would provide an evaluation model that could be applied to other training courses.

Support for participants after training

Finally the impact of training on nurses’ practice needs to be monitored and sustained. The following actions will contribute to this.

- Students are facilitated to maintain contact with one another and with their trainers during and after the training.
- Students are expected and encouraged to apply their learning in practical situations.
- Students are allocated a local mentor with whom they can discuss the initiatives they have taken with families.
- Refresher training is made available to students on an annual basis.
- In time students may become local trainers for the package.
Discussion

This project has demonstrated the complexity involved in developing training courses designed to effect national changes in service practices. A framework has emerged that could guide the development of similar training courses on other topics aimed at community nurses in Macedonia or extending the existing course to other practitioners such as social workers or early childhood educators. The framework attempts to marry local experience with information that can be gained from international experience documented in reports and research articles. Moreover the framework foregrounds the crucial role of values in the design of training inputs as these help to define the style and content of the training. Likewise the importance of re-shaping attitudes and tailoring the training inputs to the needs of adult learners are other notable features within the framework that are often neglected in traditional approaches to professional training that emphasis knowledge acquisition. Moreover the training experience needs to replicate in part – the practitioner’s reality and provide a safe context for them to practice new skills and explore the implications of changed perspectives that are promoted in the training.

The impact of the training on nursing practice remains to be evaluated as well as the benefits – if any - the nurses bring to families and children with whom they work. Plans are in hand for doing this which may well identify refinements to the package and its deployment locally and nationally. The availability of having such a planning framework arguably reduces the dependency on international consultants in low and middle income countries. In this project, the consultants brought certain advantages: notably previous experience of developing training courses for nurses; dedicated time to devote to the analysis of information gathered and to prepare training resources; along with the added kudos that comes from the sponsorship of an international agency such as UNICEF. However the danger of an over-reliance on external ‘experts’ is that the contribution of local personnel is undervalued and they are not empowered to create the solutions to the difficulties they encounter. Hopefully these dangers were ameliorated in this project by the approach used, although the real test will only become apparent in the years ahead. In particular, practitioners need to take ownership of the training endeavour and ensure that it is best suited to the needs of their service and the clients they serve. This philosophy represents a major change from current arrangements where training is delegated to university personnel who may have little direct engagement with services. Thus in low and middle income countries especially, new models of inservice training are required in order to realize low cost improvements to service delivery (Dieleman and Harnmeijer, 2006).
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Figure 1: The conceptual framework for the development of inservice training for Patronage nurses.
Table 1: The Modules in the Training Course

1. Respecting diversity
2. Understanding developmental difficulties
3. Detecting developmental difficulties
4. Promoting health and safety
5. Nurturing children’s development through play
6. Communication with the family
7. Empowering families
8. Communication with professionals
9. Rethinking the role of Patronage Nurses