IMPACT OF AN EDUCATIONAL PROGRAMME ON NURSING FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

Shira Katz and Ilana Hayout

Introduction

Advanced medical treatments and greater awareness of the needs of people with developmental disabilities (DD) have led to changes in the morbidity and mortality rates of this population (Barr, 1997; Faux and Seideman, 1995; Stanley, 1999). As a result of the above and with the acceptance of the normalisation principle in Western society (Wolfensberger; 1972), an increasing number of children with DD live in the community (Walsh et al., 2000) and receive services in general health care frameworks (Braddock and Hemp, 1997; Prouty and Lakin, 1996). DD may be defined as “any mental and/or physical disability that is manifested before age 22 years and is likely to continue indefinitely” (Whaley and Wong, 1995, p. 934). In addition, many people with DD present complex clinical pictures including autism (Folstein and Piven, 1991), cerebral palsy (Palmer and Hoon, 1995), and are the result of specific genetic syndromes, such as Down syndrome (Pueschel, 1990), and fragile X syndrome (Dykens and Hodapp, 1997; Dykens et al., 1994). Thus the field of DD has rapidly expanded and child health policy mandates services for children with special needs. As a result increasing demands for these services are being placed on nurses and other health care providers (Leonard et al., 1993).

Children with DD are at higher risk medically than healthy children, possibly due to their special health needs, inadequate health care, and the professionals' difficulty in recognising common and treatable conditions (Stanley, 1999). In addition, poor health screening and poor preventive care provided by health care professionals raise the morbidity rate of this population (Beange et al., 1995; Feeney and Kaufman, 1994; Kerr et al., 1996; Kerr et al., 1997; Stanley and Ng, 1998). This higher risk may be

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due to the fact that health care professionals appear to be poorly prepared to deal with the complex physical, emotional and psychological problems of people with DD (Faux and Seideman, 1995; Slevin and Sines, 1996; Stanley, 1998, 1999).

Another factor that may influence the level of care are negative attitudes of nurses towards persons with DD. Barr (1990) suggested in a literature review of DD that this population is viewed negatively by others in society and these negative attitudes have also been demonstrated among health care professionals, including nurses (Barr, 1990; Slevin, 1995). Slevin and Sines (1996) also found that attitudes held by nurses were generally more negative than would be expected from those in the caring profession. Examples of negative attitudes of nurses include segregating hospitalised children with DD from other ill children, and not preparing them for nursing/medical procedures due to their belief that the latter do not understand any explanations. Several studies reviewed by Fitzsimons and Barr, (1997) reported poor levels of knowledge and negative attitudes of health care professionals towards people with DD.

Research in the area of attitudes among health professionals suggest that education, exposure and experience in caring for this population may help develop more positive attitudes towards these children in general hospitals and in the community (Fitzsimons and Barr, 1997; Handler et al., 1994; Rose and Holmes, 1991; Slevin, 1995; Stanley, 1998). Similarly, studies investigating changes in attitudes among nurses toward people with DD and other mental handicaps demonstrated that exposure and experience with these populations resulted in more positive attitudes (Murray and Chambers, 1991; Singh et al., 1998). Findings in a study of student nurses indicated significantly more positive attitudes by student nurses who had clinical experience with people with DD than nurses who had no clinical experience (Slevin, 1995).

Lack of knowledge makes nurses feel inadequate in the presence of adults and children with DD (Walsh et al., 2000). This manifests itself in a lack of respect of the nurses towards children with DD and their families and may ignore the parents’ expertise in caring for their children (Stanley, 1998). The feelings of inadequacy of the nurses is often increased by the children’s poor verbal communication, difficulty of understanding and expressing pain (Barr, 1997). In conclusion, there appears to be a need for increased knowledge and training of nurses which would improve their competence, help develop more positive attitudes towards children with DD, and raise the awareness of the special needs of these children and their families (Shanley and Guest, 1995; Stanley, 1999).

Similar to other countries, general education programmes for nurses in Israel place minimal emphasis on issues relating to nursing care of children with DD. The research literature and the realities existing in Israel provided the motivation and rationale to develop a programme which would enhance the sensitivity and expertise of nurses in both the hospital and community settings. This programme focused mainly on DD such as mental retardation, autism and cerebral palsy.
Course on nursing care of children with developmental disabilities and their families

The underlying philosophy of the programme was that nursing the child with a DD and his/her family is a dynamic process directed toward meeting the normative and special needs of the child with a DD and family in hospital and community settings. An important facet of this philosophy is that nursing is holistic and is based on family centered care aimed at providing nursing care to all children up to the age of 18, regardless of race, color, creed, sex and economic and health status (UKCC, 1992). The provision of high quality nursing care for children in general and children with DD is dependent on the knowledge, skills and clinical experience of the nurse (Walsh et al., 2000).

The coordinators of the course initiated and planned the nursing programme in cooperation with a special school for children with severe DD and a children’s hospital in the centre of the country. The special school provided the premises for the implementation of the course. The 24 participants included pediatric nurses from different wards in the children’s hospital (HN) and public health nurses (PHN) from the Ministry of Health working with children with special needs in the community. Nurses from both hospital and community frameworks were included to increase the awareness of the role of the nurse in the care of children with DD and their families in different nursing frameworks. Furthermore, the purpose of the course was to provide opportunities for an exchange of ideas, attitudes, dilemmas and practices between the two groups of nurses.

Goal of programme

The overall goal was to enhance the quality of nursing care provided to children with DD and their families in hospital and community based frameworks. The specific objectives were:

1. To enhance awareness of the special and normative needs of children with DD and their families.
2. To increase knowledge relating to DD in children.
3. To acquire nursing skills to care for children with DD.
4. To increase knowledge relating to the implications of the child’s DD on the family.
5. To enhance nursing skills to care for the family with a child with DD in community and hospital settings.

Profile of participants

Participants in the programme included 15 female pediatric registered nurses (HN) working in the children’s hospital and 9 public health nurses (PHN) working with children in the community. As can be seen in TABLE I, important differences were found between the two groups of nurses. Whereas a large majority (88.9%) of PHNs were over the age of forty, the majority of HNs were much younger. Except one nurse, all the PHNs had participated in public health post basic courses, and two thirds of the group had higher academic degrees. Among the HNs, just over half had received higher academic degrees and over one half had participated in a post basic pediatric and other courses. PHNs had far more general and pediatric nursing experience and held higher positions at their workplaces.
Whereas all the HNs had cared for children with DD in the hospital, one third of the PHNs reported neither providing nursing caring nor personally being acquainted with this population. (These nurses worked in preventive health clinics in the community). Despite their previous nursing experience with children with DD, the majority of nurses expressed lack of confidence in caring for these children and families, and lack of knowledge and skills to provide quality care.

Initially, 27 nurses started the course. However, after the second meeting three nurses dropped out of the programme; one because of personal reasons and two because they felt that they could not cope emotionally with children with DD.

**TABLE I**
Profile of Participants

<table>
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<th></th>
<th>PHN (n=9)</th>
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<td>Years of Pediatric Nursing Experience</td>
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<td>5</td>
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<tr>
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<td>4</td>
</tr>
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<td>11-15</td>
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<td>16+</td>
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<td>Nursing Role</td>
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<td>Ward head nurse</td>
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<tr>
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<td>0</td>
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<tr>
<td>Nursing contact</td>
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<td>14</td>
</tr>
<tr>
<td>Family member with DD</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

PHN - Public Health Nurse
HN - Hospital Nurses
Description of Programme

The programme consisted of eight hours of studies once a week over a period of 14 weeks. At the request of the participants, an additional day of eight hours studies was added six months later to include issues such as religion, ethics and DD, and to evaluate the course (all inclusive -120 hours of studies). Lecturers included the coordinators of the programme, the multidisciplinary team from the special school (physiotherapist, occupational therapist, speech therapist and special education teachers) and outside lecturers (parents of children with DD, genetic counsellor, psychologist etc.). The contents of the programme were divided into two parts.

(1) Theoretical studies included history of nursing children with DD, rights of children with DD, types and treatment of DD, genetics, implications of DD on the child and family, coping behaviours and adaptation of families with a child with DD, and local and national facilities providing services for children with DD. Throughout the studies emphasis was placed on the role of the nurse in the care of this population in community and hospital frameworks.

(2) Clinical experiences included observations and discussions with the multidisciplinary team at the special school. In addition, visits to different institutions for children with DD were arranged for all the nurses. In the eighth week of studies each participant started implementing a nursing intervention plan in a home of a child with a DD and his/her family for a period of six weeks. The goals for the semi-structured programme for the home visits included contract agreement, child and family assessment, identification of problems, implementation and evaluation of nursing intervention plans. During this period, weekly discussions were held and participants received feedback from the nurses and coordinators of the programme. In addition, on the basis of the theoretical studies and the feedback received from the group members, further objectives for the nursing plans were set up. Throughout these discussions the nurses were encouraged to share their feelings of ambivalence, emotions and attitudes towards the children and their families. Expression of feelings was encouraged so as to provide an effective cognitive facet to the training programme. The rationale for this is that learning is more affective if both cognitive and emotional components are present (Singh et al., 1998). In this part of the programme emphasis was placed on the difficulties the family encountered and the variables affecting their coping behaviours. The group members shared ideas and previous experiences with similar families in order to find alternative coping strategies to assist the family to adapt to the situation. At the completion of the course, the nurses in groups of two to three participants prepared written nursing intervention programmes for children with DD and their families relevant to their workplace. In addition, each nurse prepared a written report of her visits and intervention with the family.

Evaluation

A written evaluation form was filled out by all the participants on the last day of the course. A second evaluation of the contributions and impact of the course was carried out six months after the completion of the course.
Instruments for first evaluation

1. A demographic questionnaire relating to age, education, years of general and pediatric experience, nursing role, and previous contact with children with DD. (TABLE I)

2. An evaluation questionnaire was designed by the coordinators to determine the nurses’ responses to the contributions and relevance of the course. This questionnaire was divided into two parts. The first part consisted of five categories (with 4-9 questions in each category). The specific categories in the course related to the expectations from the course, the theoretical and clinical contents, the implications and importance of the course, the contribution of outside lecturers and specific subjects, and one question relating to general satisfaction with the programme. The participants were requested to respond to the questions on a scale from 1 (very much), 2 (somewhat), to 3 (not at all).

The second part of the questionnaire for participants consisted of four additional questions. The first question related to the length of the course on a scale from 1 (too long), 2 (appropriate), to 3 (too short). The last three questions related to the relevance of the subjects, subjects lacking or inappropriate to the course, and the suitability of the facility chosen to implement the course. Participants were requested to reply either yes or no to the last three questions and to add their comments.

Scoring - The final scores of the first part of the questionnaire were attained by summing over the replies to the questions in the five categories. In the second part of the questionnaire, a separate score was attained for each question. This questionnaire was filled out by the participants on the last day of the course.

Instruments for second evaluation

Six months after completion of the programme a workshop was held for all the participants to evaluate the long-term implications of the course. The nurses were requested to fill out a short evaluation form consisting of four questions on a scale 1-3 (a great deal, somewhat and not at all). These questions related to the contribution of the course on the quality of care provided to children with DD, the impact of the course on their colleagues, the importance of implementing the course for other groups of nurses, and the importance of including nurses from different frameworks in the course. An additional question related to programmes and nursing plans carried out since the completion of the course. The nurses were requested to reply either yes or no, and if they replied in the affirmative, were asked to qualify their responses. The scoring was carried out by summing up questions 1 and 2, which related to the contribution of the course, and summing up questions 3 and 4, which related to the importance of the course. Question 5 was scored separately.

Results and Discussion

The purpose of the evaluation was to determine whether the programme on DD in children had achieved its goal and objectives. The results of the first part of the evaluation at the completion of the courses are presented in TABLE II.
TABLE II
Evaluation at Completion of Course

<table>
<thead>
<tr>
<th>Categories</th>
<th>Very Much</th>
<th></th>
<th>Somewhat</th>
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<td></td>
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<td></td>
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<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Expectations</td>
<td>HN</td>
<td>13</td>
<td>87</td>
<td>2</td>
<td>13</td>
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<tr>
<td>Knowledge and Skills</td>
<td>HN</td>
<td>12</td>
<td>80</td>
<td>3</td>
<td>20</td>
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<tr>
<td>Specific Content</td>
<td>HN</td>
<td>15</td>
<td>100</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Implications and Importance</td>
<td>HN</td>
<td>14</td>
<td>93</td>
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<td>7</td>
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<tr>
<td>Satisfaction</td>
<td>HN</td>
<td>13</td>
<td>87</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

PHN - Public Health Nurse (n=9)
HN - Hospital Nurses (n=15)

Evaluation at the completion of the course

As can be seen from TABLE II, overall the large majority of nurses reported that the course fulfilled their expectations and increased their knowledge and nursing skills to care for the child with DD and his/her family. They felt that the specific additional subjects contributed to their knowledge and practice, and that their colleagues would benefit from the course. However, there were differences between the HNs and PHNs. While the large majority of HNs expressed greater satisfaction with the course, PHNs were divided in their responses. The PHNs were more reserved in their evaluations and a smaller percentage responded “very much” to the questions than the hospital nurses. The differences between the answers to the evaluation form of the HNs and the PHNs were obviously influenced by their nursing role, experience and relative expertise. The hospital nurses claimed to have little or no knowledge in the field of DD in children at the beginning of the programme. Despite this, both groups expressed satisfaction with the course and they felt that the inclusion of both groups in the programme was very important and beneficial for all nurses. The group provided the opportunity for an exchange of ideas relating to the provision of nursing services at all levels of health care. In addition, it also improved the channels of communication between HNs and PHNs. One aspect of this communication was the clarification of the roles of the participants in different health care settings. The PHNs felt that although they benefited from the combined course, they would also like to have in addition, a separate, more advanced level course geared to their level of knowledge and expertise.

With regard to the last three questions, 53% of the HN nurses were satisfied with the length of the course, whereas 33% of them stated that it was too short. In the group of PHNs, 55.6% approved of the length of the course, while 44.4% felt that
it should have been longer. The participants stated that the subjects and clinical experiences were relevant, and despite the fact that the PHN came from all over the country, 100% of all the participants expressed great satisfaction with the facility where the course took place.

In addition to the evaluation forms, weekly discussions evaluating the home visits were held. Whereas initially the hospital nurses reported feeling inadequate, uncomfortable and hesitant to advise the families, they demonstrated a growing awareness and sensitivity to the special needs of the child with DD and family. By the end of the course the nurses expressed greater self-confidence and ability to implement similar nursing plans at their place of work. The PHNs reported satisfaction with the structured framework for the implementation of the nursing plan and felt that it was beneficial for their work. It appears that the impact of exposure and clinical experience with children with DD, and the support, reinforcement and feedback received from the group members helped the nurses to provide quality care to this population. Examples of group projects prepared by the nurses included nursing care plans for the child with autism, the child with a DD in the hospital, and assessment of the child with a DD in special schools.

**Evaluation after six months**

Twenty one nurses participated in the workshop that was held six months after the completion of the course. The participants were requested to fill out a questionnaire relating to their perception of the contributions and implications of the course. Eighty one percent (n=17) of all the nurses reported that the course contributed a great deal to the increase in the quality of care they provided to children with DD, whereas 19% (n=4) reported that the course had contributed somewhat to the care they provided to this population. In response to the question whether the colleagues of the nurses benefited from the course, 52% (n = ll) reported “a great deal”, 38% (n=8) reported “somewhat” and 9% (n=2) reported “not at all”. Ninety five percent (n=20) of all the nurses felt that it was very important to organise similar courses for other nurses, and 5% (n=1) felt that it was “somewhat” important. The fourth question related to the contribution of integrating HNs and PHNs in the course. Eighty six percent (n=18) stated that it contributed “a great deal”, 10% (n=2) stated “somewhat” and 5% (n= 1) stated “not at all”. Sixty seven percent (n=14) reported planning and implementing programmes relating to nursing care of children with DD, whereas 33% (n=7) had not done so. A number of nurses in the latter group reported plans to do so in the future. In reply to this question, the nurses specified lectures and programmes they had implemented in their respective place of work and other nursing frameworks.

The evaluations carried out at the completion of the course and six months later indicated that the large majority of nurses perceived the course as being important and felt that it had contributed to the quality of care they provide to children with DD and their families. In the first evaluation nurses discussed plans and methods to share their newly attained knowledge with their colleagues. In the second evaluation, over two thirds of the nurses reported having implemented programmes, given lectures etc. It appears that after a six month period the course still had a positive impact on the nurses.
In conclusion, on the basis of the evaluations and discussions with the nurses, Ministry of Health officials and hospital management, the programme appeared to fulfill its goals and objectives. Furthermore, workshops and lectures have been organised and requests for additional courses for nurses in the hospital and community have been received. The children’s hospital is presently preparing a similar course for nurses as part of their in-service training.

**Conclusion**

If the nursing profession strives to improve the quality of care provided to children with DD and their families, it is crucial to increase the knowledge and skills of nurses in this field. Comprehensive educational programmes in issues related to DD including clinical experience and exposure to children with DD in various settings will enhance the quality of care provided to this population. In addition to this, there is a need to adjust undergraduate nurse education programmes to include the field of DD in children (Parrish and Sines, 1997) and to organise ongoing continuing education programmes to enhance the knowledge and skills of all nurses (Walsh et al., 2000). Without this education and experience the attitudes of the nurses will remain the same as that of the general public (Shanley and Guest, 1995).

Children with DD have the right to expect health care appropriate to their needs (Kerr, 1995). Families need to be assured that care is provided by professionals who are knowledgeable in the field and the special health care needs of their children (Steele, 1990). Nurses need to be advocates for these children and their families (Seal, 1998), be familiar with disability laws, local and national services available to these families (Kastner et al., 1999), and acquire skills to work with a multidisciplinary team (Walsh et al., 2000). Specific nursing knowledge and skills relating to children with DD enables the nurse to play an important role in the multidisciplinary team (Parrish and Birchenall, 1997).

The growing number of children with DD in the community will present an increasing challenge for nurses [DoH (Dept. of Health) 1995] and it is the duty of the nursing profession to prepare them for this task. Provision of a comprehensive educational background will strengthen the attitudes and behaviours of nurses towards children with DD and their families (Barr, 1997; Hastings, 1997).

**Summary**

A review of the literature indicates that people with developmental disabilities (DD) are viewed negatively by health care professionals, including nurses. Research in the area of attitudes of health care professionals towards this population suggest that education, exposure and experience in caring for people with DD help develop more positive attitudes, understanding and provision of higher quality care. The purpose of this programme was to enhance the quality of nursing care provided to children with DD and their families in hospital and community based frameworks. The programme included theoretical studies, clinical experiences, and implementation of nursing intervention plans. Twenty four nurses from a children’s hospital and from the community participated in the programme. Evaluation carried out at the
end of the course and six months later indicated that the programme enhanced their ability to provide quality care to the children with DD.

References


Prouty, R.W. and Lakin, K.C. (Eds.). (1996). Residential services for persons with...
developmental disabilities: Status and trends through 1995. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.


