Title: Evidence-based training of health professionals to inform families about disability

Contributors:
Alison Harnett(1), Erin Bettendorf (2), Edel Tierney(1), Suzanne Guerin(3), Margaret O’Rourke (4), Jonathan Hourihane (4)

1) National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability, Galway, Ireland.
2) Harvard Medical School, Boston, Massachusetts, US.
3) School of Psychology, University College Dublin, Ireland.
4) School of Medicine and Health, University College Cork, Ireland.

Correspondence to: Alison Harnett, Informing Families Project Coordinator, National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability, Oranmore Business Park, Oranmore, Galway, Ireland; Alison.harnett@fedvol.ie (TEL: +353 91 792316, FAX: +353 91 792317)

Keywords:
Disability, communication skills, training, evaluation, informing families, disclosure
ABSTRACT

**Objective:** The development, delivery and evaluation of a training programme for medical and nursing professionals on best practice for informing families of their child’s disability.

**Design:** A two-hour training course on ‘Best practice guidelines for informing families of their child’s disability’ [1] was designed based on the findings of a nationally representative study of parents and professionals [2]. The classroom-based course comprised a presentation of the research and recommendations of the best practice guidelines; a DVD film of parent stories and professional advice; group discussion; and a half-hour input from a parent of two children with disabilities. An anonymous, pre- and post-training questionnaire was administered to measure knowledge and confidence levels, using scales adapted from a study by Ferguson et al (2006) [3].

**Participants:** 235 participants including medical students, nursing students, and junior hospital doctors (JHD’s).

**Outcome Measures:** Knowledge of best practice and confidence in communicating diagnosis of disability

**Results:** Significant improvements in knowledge (Time 1 M=14.31, SD=2.961; Time 2 M=18.17, SD=3.068) and confidence (Time 1 M=20.87, SD=5.333; Time 2 M=12.43, SD=3.803) following training were found. In addition a significant interaction between Time and Cohort (Medical students, Nurses and JHDs) was found for knowledge. Further examination suggested medical students’ knowledge was developing to the extent that post training, their scores were higher than nurses but not significantly different to JHDs.

**Conclusions:** The increase in reported levels of knowledge and confidence following training in best practice for informing families of their child’s disability indicates the potential for providing communication skills training in this area.
INTRODUCTION

The way that communication is handled when a family is informed of their child’s disability has the potential to impact on adjustment. Good disclosure practice prevents much distress for parents, can form the beginning of positive relationships between parents and professionals, facilitates the attachment process, and when combined with family support services, reduces levels of anxiety and stress [4]. However, previous studies have found varying levels of satisfaction with the disclosure process amongst parents of children with disabilities, with a significant proportion of families reporting dissatisfaction with the way that they received the news of their child’s diagnosis [5, 6]. Harnett et al, (2007) found that 27.2% of parents of children with physical, sensory and intellectual disabilities reported some level of dissatisfaction with how they had been informed.

A broad range of professional disciplines are responsible for informing families about their child’s disability (or raising concerns) depending on the diagnosis type, timing and the service context [7]. The diagnosis can be given by professionals with varied levels of experience and confidence, in various service settings, and by medical, nursing and allied health professions [2]. For some this is a responsibility which occurs regularly but for many others this is required only periodically [2]. Numerous studies have demonstrated the effectiveness of providing general communication skills training for healthcare professionals [8,9,10] and specific changes have included improvements in self-rated confidence, knowledge and overall communication skills [8,11,12], as well as reports of better and more satisfying consultations for both doctors and patients [13]. Studies have shown training effects persist months after the training has occurred and patients have rated doctors who have completed training more highly after 3 months [13, 14]. Past participants in communication skills training generally rate the experience highly and consider it to be worth their time [8, 13]. Furthermore, many would recommend the training to their colleagues [10].
Despite positive benefits of training, the level of communication skills training provided varies considerably. Some studies report that postgraduate health care professionals have received low levels of formal training in breaking difficult news, showing between half and three-quarters of respondents without any previous instruction [7, 10]. Other studies found that those who had recently completed their education had largely received training in breaking difficult news [15]. The risk of litigation is increased when poor communication is used at the time of diagnosis [16]. Significant improvements in knowledge among paediatric and obstetrics/gynecology physicians have been found when training is provided for communicating a diagnosis of Down Syndrome [3].

The Present Study

Evidence-based best practice guidelines for informing families of their child’s disability were developed in an earlier study in the Republic of Ireland [2]. The results of this study produced the National Best Practice Guidelines for Informing Families of their Child’s Disability [1]. This paper describes the development, delivery and evaluation of a training programme for medical and nursing professionals based on these guidelines.

METHODS

Procedure for Training Development

The qualitative and quantitative findings from the original study [2] were reviewed to develop a classroom based training programme, focused on the recommendations for best practice [1]. On the basis of the review the following elements were included in the training programme: 1) group discussion to elicit and respond to the particular learning needs and concerns of the training participants; 2) a DVD film of parent stories and professional advice based directly on the research findings from the guideline development; 3) presentation of the research and
recommendations of the guidelines; 4) classroom input from a parent describing her personal experience of receiving a child’s diagnosis. A pilot project (described elsewhere) was set up in one geographical region in the south of Ireland to evaluate the implementation of the best practice guidelines and this provided an opportunity to evaluate the training programme.

Training Evaluation

Participants

As part of the pilot project the training course was delivered to a total of 235 participants including 80 4th year medical students, 130 2nd year nursing students and post-graduate Public Health Nurses (PHNs), and 25 Paediatric and Neonatal Non-Consultant Hospital Doctors (JHDs). Participants were chosen for the study using an opportunistic purposive sampling process. 154 participants completed pre and post training questionnaires and were therefore included in the evaluation. This group consisted of 29 medical students, 108 nursing students/PHNs, and 17 JHDs.

The Clinical Research Ethics Committee of Cork Teaching Hospitals confirmed that the study was exempt from requiring full ethical review, as it was an anonymous survey of student feedback on training with no patient involvement.

Measures

Anonymous pre- and post-training questionnaires were administered to participants (matched using partial telephone numbers). In the absence of standardised measures for evaluating training in the disclosure of a child’s disability it was decided to adapt a questionnaire used by Ferguson et al (2006) which had been used to evaluate the implementation of training materials for disclosure of a Down Syndrome diagnosis. The existing questionnaire contained measures for Comfort and Knowledge. The Comfort measure (Situational Inventory) has face
validity in that the authors had consulted with a medical and expert parent team to construct common situations that practitioners would likely face in delivering a diagnosis.

In adapting Ferguson's questionnaire, Confidence had been identified as an important factor in the training, based on the findings of the national Informing Families study. Questions were devised to ask how confident the participants felt in their knowledge of good practice to be used in each of the key areas relevant to the process of informing a family of their child’s disability, as identified in the guidelines: Setting/Location and People Present; Communication; Information and Support; Culture and Language; Organisation and Planning. (The area of ‘Information and Support’ was divided into two questions; one on Information and one on Support to reflect the level of deficit in previous good practice identified in this area through the national Informing Families study).

The structure of the Comfort measure used by Ferguson et al was then replicated with a 5 point Likert scale to ask participants how confident they felt in their knowledge of the particular area of practice under question, for example “You know what to do if presented with a family who have limited or no English, when communicating difficult news about their child’s diagnosis” or “You know what kinds of written information should be supplied to the family at the time of diagnosis”.

The Knowledge section of the questionnaire explored knowledge of best practice. The Knowledge pre- and post tests used by Ferguson et al consisted of multiple choice items. For the Knowledge portion of the questionnaire in the present study the authors replicated the multiple choice structure of the Ferguson measure in which the participant is provided with typical scenarios that occur around the diagnosis (as identified by parents and professionals) and is given a range of options in terms of actions that could be taken, one of which represents
best practice. As the range of disciplines to be targeted by the training in the present study was wider than that in the Ferguson study, and since the knowledge required relates to a wider range of disabilities, the scenarios presented were adapted and the national Informing Families study was used to identify typical situations that the participants might find themselves in when communicating with families. To the five multiple choice questions, an open-ended question was added asking participants to list six elements of good practice that they thought important when informing families of their child’s disability. The questionnaire was then reviewed by professionals with expertise in both research methods and disclosure of disability.

The Confidence section of the questionnaire consisted of six questions in which respondents indicated their level of confidence in aspects of communicating a child’s diagnosis on a five point scale (1 = Extremely Confident, 5 = Not at All Confident). Overall mean scores were calculated with low scores indicating positive ratings. The responses to the open-ended question in the Knowledge section of the questionnaire were scored for accuracy based on the Best Practice Guidelines [1] as follows: 0= incorrect, 1= partially correct and 2= fully correct. The data in each question of the multiple-choice ‘Knowledge’ section were scored in the same manner. A total Knowledge score was then calculated, with a possible range of 0 to 22 and higher scores indicating better knowledge of the best practice guidelines.

**Statistical Analyses**

The pre- and post-training questionnaires were matched according to the five digit partial phone number provided by participants. Data were entered into SPSS version 17.0 and no serious or consistent errors were identified during a data check. Inter-rater reliability of categorisations and scorings of the Knowledge section was carried out. This identified an 87.8% agreement rate, which was taken to represent appropriate inter-rater agreement [17].
The data were analysed using two-way ANOVAs, exploring both the main effect of Time (Pre vs Post-Training), and the interaction of Time and Cohort (Medical Students, Nurses and JHDs). The main effect for cohort was not examined as interaction with Time was deemed to be central to the analysis. A test of simple effects was used as this allows for closer examination of the nature of an interaction, specifically the presence of significant differences within the overall interaction.

RESULTS

Content and delivery of training programme

The development procedure described above resulted in a two hour classroom-based training course which was guided by the 6 key principles of family centred disclosure; respect for child and family; sensitive and empathetic communication; appropriate and accurate information provision; positive, realistic messages and hope; the importance of the team approach and planning for disclosure.

A set of questions was devised to guide group discussion and identify key areas of concern and learning need from each group of trainees (e.g. what are the circumstances in which you are typically involved in the disclosure process; which elements of the communication do you find most challenging?). In addition the Best Practice Guidelines and research evidence supporting them were structured into a half hour presentation, delivered together with a copy of the guidelines for each participant in training.

A 24 minute film ‘Words You Never Forget’ [18] was produced to depict two family stories as told by the parents; one in which the family had received their diagnosis in a way that followed best practice and one in which the news had been given in a way that added to the
distress of the parents. The stories were selected as being representative of the positive and negative experiences that had emerged from the national study [2]. The presentation of the two stories was structured to follow and reinforce the recommendations of the best practice guidelines, i.e. covering particular areas such as communication skills, physical environments where the diagnoses took place, information provision; presence or absence of positive messages, etc. The film also portrayed interviews with professionals in a regional maternity hospital, a regional paediatric hospital, and a Community Based Early Intervention Service, in order to provide advice from staff members who are regularly involved in communicating the news of a child’s diagnosis to families.

Finally, the researchers worked with a mother of two children with disabilities who prepared a half-hour presentation describing her personal experience, particularly how she had been informed of their diagnoses and the impact of this communication. Parent participation in the delivery of training provided an opportunity to ground the training in personal experience to assist the students in identifying with families and to encourage empathetic responses.

It was judged that two hours would allow for the maximum release of staff members to attend. It was not possible to provide a role-play or experiential element of training in the two hours available for training delivery, although this would be a desirable element if time allowed. Although there was an initial intention to ask participants to watch the DVD film ahead of classroom time, in practice it was shown as part of the programme, as it was not possible to ascertain with confidence that all students would find time to watch before attending.

**Evaluation findings**

Table 1 presents the mean scores from pre-training and post-training across the three cohorts (Medical Students, Nurses, JHDs). It should be noted that the Confidence and Knowledge
domains are scored in different directions i.e. that a lower score in the confidence domain is more positive whilst a higher score in the knowledge domain is more positive.

ANOVA analyses identified significant main effects for Time for both Confidence (F = 193.836, df = 1, 147, p < 0.05) and Knowledge (F = 127.919, df = 1, 132, p < 0.05), and examination of the mean scores suggests improvements in both scales (an increase in confidence and an improvement in knowledge). In addition, while there was no evidence of a significant interaction with Cohort for Confidence (F = 1.869, df = 2, 147, p > 0.05), a difference was evident for Knowledge (F = 5.401, df = 2, 132, p < 0.05). This suggests that there is evidence for differential change among certain groups over others in Knowledge but not in Confidence. The interaction was plotted (See Figure 1) and a Test of Simple Effects was conducted to examine this interaction.

Table 2 presents the breakdown of the findings from the tests of simple effects. This analysis revealed that each of the groups showed a significant increase in Knowledge. However the examination of Cohort differences at Time 1 and Time 2 revealed a more complex pattern. The results show no difference before training between medical students’ and nurses’ knowledge levels, with both groups showing significantly lower knowledge levels than JHDs. After training however there was no difference between the medical students’ and JHDs’ knowledge levels, but the levels reported by nurses were significantly lower than both.

**DISCUSSION**

Strategies for implementing best practice when informing families of their child’s disability have been found to lack effectiveness because one third of key staff members were unaware of guidelines [19]. This paper describes the development, delivery and formal evaluation of a

---

1 'f' represents \( f_{\text{observed}} \) - the observed difference between the groups. 'df' = degrees of freedom
training programme for medical and nursing professionals based on best practice guidelines in this area. This involved developing a time-limited training input that would allow for wide-scale staff-release and for repeated running of the programme each time staff move on rotation. A corresponding disadvantage was that there was insufficient time to include a role-play element in the training during this study. However, it is recommended that a role-play or experiential element to training should be added in future programmes and should be evaluated in future studies. Practical considerations learned during the process included the need to show the training DVD during class time rather than providing it ahead of time for students to watch in their own time. A key component of the successful roll-out of training was to identify champions in each discipline and to secure support from health service managers and lecturers/senior academics, since it can be difficult to gain access to already packed curricula and induction modules.

The training programme was delivered to a group of Medical students, Nursing students and Junior Doctors (JHDs) and overall significant improvements in knowledge and confidence were identified. However in examining a significant interaction between change and cohort it was found that while each group showed improved knowledge, medical students showed the most development, with the scores being lower than JHDs and comparable to Nurses at Time 1, but higher than Nurses and comparable to JHDs at Time 2. One potential explanation for the initial higher levels of knowledge of JHDs compared with medical and nursing students before training is that this cohort had significantly more direct interaction with families and would therefore have gained more frontline experience. Nevertheless the findings suggest positive changes in confidence and knowledge following the training.

However a number of limitations exist. Participation in the training program and completion of the questionnaires was voluntary- students and health care professionals were informed of
the training and invited to join, but they were neither required to attend nor required to complete the questionnaire(s). This may have caused selection bias in the responses gathered. The findings in relation to group differences must be considered in the context of the samples achieved. The dominance of nursing students might suggest a more reliable sample, however, given that neither group were randomly selected, the potential for samples to be biased is a limitation. However, as medical and nursing students share many modules of education in the institution, differences found between cohorts are more likely to be real than perceived. As there is no control group to which the training participants can be compared, it is not possible to definitely attribute the changes identified to the impact of the training. Also, it is important to note that this study focused on self-report by participants and that improvements in self-reported confidence may not necessarily lead to improvements in clinical practice [20]. It is possible that participants may increase their self-ratings to indicate that the training was worth their time or enjoyable rather than showing that their skills actually increased [21]. It was not possible in this study to evaluate the disclosure practice of participants following their participation in the training. As the assessment of confidence is self-reported and therefore qualitative and subjective and since the results regarding participants’ knowledge is pertinent to the time of assessment in this study, there is a need for further studies to gauge the effects of this type of training on outcomes including parent satisfaction and practitioner-family relationships. To test actual clinical improvements, family evaluations of the participants or other external assessments would be needed.

**Conclusions**

The improvements in levels of confidence and knowledge reported by participants of the training programme demonstrate the potential benefits of providing communications skills training that specifically addresses the needs of families at the time of their child’s diagnosis with a disability. The wide range of professionals and broad range of experience levels
involved in disclosure of childhood disability [2] indicate the need for training to be delivered across medical, nursing and allied health disciplines. Previous studies had examined the provision of training in best practice for communicating the diagnosis of Down Syndrome [3]. This study supports the benefit of providing training with regards to a wider range of physical, intellectual and sensory disabilities.

The two-hour programme designed through this study is now delivered on an annual basis to Paediatric trainees at the Royal College of Physicians of Ireland. It is also delivered on a range of undergraduate and post-graduate nursing and medical courses around the country. A ‘Train the Trainers’ programme has been provided in order to broaden the reach of the programme and to sustain the roll-out of the training across different settings. Elements of the programme have also been provided as an e-learning module on www.informingfamilies.ie to further secure access to the training for professionals in practice.

Whilst it would be preferable to provide a broader, more comprehensive training programme that includes a role-play element, this study found that a pragmatic approach to dissemination and training leads to broader implementation. Meeting this wide range of need in delivering a two-hour programme appears to have the potential to impact positively on medical and nursing professionals.

Acknowledgements
The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability; the Irish Health Services National Partnership Forum; Cork University Hospital; Cork University Maternity Hospital; University College Cork; University College Dublin; Dr. Kerim Munir, Harvard Medical School and the National Institute for Mental Health; the ‘Brighter Tomorrows’ Programme, Dr. Harold Kleinert, Dr. James E Ferguson and Dr. Carol
Lunney. Particular thanks are due to the Steering Committee of the Informing Families Cork Implementation Project and its Evaluation Working Group. We appreciate the contributions of the parents and professionals to the production of the ‘Words You Never Forget’ film and particular thanks are due to Ms. Katherine O’Leary, parent and Chair of the Informing Families Cork Implementation Project for delivery of the training and sharing of her personal story with the trainees. Participation of EM Bettendorf in this project was funded by the Mental Health/Developmental Disabilities Grant (NIMH/NIH R25 MH071286) at Children's Hospital Boston (Dr. K. Munir, PI).

**Contributorship Statement**

[Alison Harnett (AH), Erin Bettendorf(EB), Edel Tierney (ET) Suzanne Guerin(SG), Margaret O'Rourke (MOR), Jonathan Hourihane (JH)]

Study design SG, AH, ET, MOR and JH; supervision of study and methodology SG and ET; literature review AH and EB; training delivery AH; data entry EB; statistical analysis SG, AH and EB; write up of drafts AH, EB & SG; review of drafts all authors; sampling and access to populations studied JH and MOR. Coordination of write-up and responsible for overall content, AH.

**Funding**

Participation of EM Bettendorf in this project was funded by the Mental Health/Developmental Disabilities Grant (NIMH/NIH R25 MH071286) at Children's Hospital Boston (Dr. K. Munir, PI). Funding for the wider pilot project of which the current study forms a part, was provided by the Health Services National Partnership Forum and the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disabilities.
Competing Interests

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: EB received grant funding from the Mental Health/Developmental Disabilities Training Research Training Grant (NIMH/NIH R25 MH071286) at Children’s Hospital Boston (Dr. K. Munir, PI) and funding for medical student summer research projects from Harvard Medical School Office of Enrichment Programs for the submitted work. No support was received by any other authors from any organisation for the submitted work; JH had Consultancy with Danone, Grant funding from the Food Standards Agency, UK, Danone, and the Health Research Board, Ireland and payment for lectures from Stalleregens, MSD and Danone in the previous 3 years. JH is the co-inventor of a food allewregen challenge outcome predictor. MO’R had consultancy work with the Health Services Executive regarding child protection, and received payment for the development of educational presentations for LIFEMATTERS and SAFEMED. AH received travel expenses for the provision of training to medical students in the University of Limerick and Paediatric Junior Doctors from the Royal College of Physicians subsequent to the study completion. All other authors had no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work.
What is already known on this topic

- How families are informed of their child's disability has an impact on parental stress, parental satisfaction, and can affect the parent-professional relationship thereafter.
- Better communication leads to less likelihood of litigation.
- Professionals have expressed their need for increased training, guidance and support in the disclosure process.

What this study adds

- Training in evidence-based best practice guidelines in this area produced positive effects on knowledge and confidence in medical and nursing/midwifery students and junior doctors.
- Training was effective for a wider range of physical, sensory and intellectual disabilities, having previously been found effective for disclosure of Down Syndrome diagnoses.
- While all groups benefited from training, improvements were higher for medical students. Specific strategies may be needed to improve confidence of student nurses.
References


15. Horwitz N, Ellis J. Paediatric SpRs’ experiences of breaking bad news. *Child Care Hlth Dev.* 2007;33:625-630


The Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, an exclusive licence (or non-exclusive for government employees) on a worldwide basis to the BMJ Group and co-owners or contracting owning societies (where published by the BMJ Group on their behalf), and its Licensees to permit this article (if accepted) to be published in Archives of Disease in Childhood and any other BMJ Group products and to exploit all subsidiary rights, as set out in our licence.
Tables & Figures

Table 1: Mean scores for Confidence and Knowledge of participants pre and post-training

<table>
<thead>
<tr>
<th>Variable</th>
<th>Cohort</th>
<th>Time 1 M (SD)</th>
<th>Time 2 M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidence</td>
<td>Overall</td>
<td>M=20.87 (SD=5.333)</td>
<td>M=12.43 (SD=3.803)</td>
</tr>
<tr>
<td></td>
<td>Medical Students</td>
<td>M=22.43, (SD=4.985)</td>
<td>M=12.54 (SD=4.509)</td>
</tr>
<tr>
<td></td>
<td>Nurses</td>
<td>M=20.89 (SD=5.467)</td>
<td>M=12.54 (SD=3.706)</td>
</tr>
<tr>
<td></td>
<td>JHD</td>
<td>M=18.18 (SD=4.081)</td>
<td>M=11.53 (SD=3.184)</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Overall</td>
<td>M=14.31 (SD=2.961)</td>
<td>M=18.17 (SD=3.068)</td>
</tr>
<tr>
<td></td>
<td>Medical Students</td>
<td>M=14.38 (SD=3.437)</td>
<td>M=19.93 (SD=2.374)</td>
</tr>
<tr>
<td></td>
<td>Nurses</td>
<td>M=13.93 (SD=2.792)</td>
<td>M=17.42 (SD=3.061)</td>
</tr>
<tr>
<td></td>
<td>JHD</td>
<td>M=16.31 (SD=2.213)</td>
<td>M=19.19 (SD=2.738)</td>
</tr>
</tbody>
</table>

Table 2: Findings from the Test of Simple Effects

<table>
<thead>
<tr>
<th>Effect tested</th>
<th>Test of Simple Effects</th>
<th>Direction</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1 vs T2 Medical Students (MS)</td>
<td>F = 86.993, df = 1, 132, p &lt; 0.05</td>
<td>T1 &lt; T2</td>
</tr>
<tr>
<td>T1 vs T2 Nurses (N)</td>
<td>F = 106.757, df = 1, 132, p &lt; 0.05</td>
<td>T1 &lt; T2</td>
</tr>
<tr>
<td>T1 vs T2 JHD</td>
<td>F = 12.924, df = 1, 132, p &lt; 0.05</td>
<td>T1 &lt; T2</td>
</tr>
<tr>
<td>Cohort differences at T1 (MS vs N vs JHD)</td>
<td>F = 7.512, df = 2, 132, p &lt; 0.05</td>
<td>N = MS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N &lt; JHD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MS &lt; JHD</td>
</tr>
<tr>
<td>Cohort difference at T2 (MS vs N vs JHD)</td>
<td>F = 15.299, df = 2, 132, p &lt; 0.05</td>
<td>N &lt; MS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N &lt; JHD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MS = JHD</td>
</tr>
</tbody>
</table>
Figure 1. Improvement in knowledge per cohort before vs after training
(Numerical data for Figure 1 as per data presented above in Tables 1 and 2.)