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Title: ‘Tell it Right, Start it Right’: an evaluation of training about Down syndrome for health professionals

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Title: “Tell it Right, Start it Right”: an evaluation of training about Down syndrome for midwives and other health professionals

ABSTRACT

Midwives do not routinely receive training in how to manage parent care when Down syndrome (DS) is identified in pregnancy or after birth. Many parents report dissatisfaction

with the response of health professionals during this time. In response, the UK Down's syndrome Association has developed the "Tell it Right, Start it Right" training. This research evaluated the training using the Kirkpatrick Model. A repeated measures online survey was delivered before training, immediately after training and two months after training. Midwives constituted the majority of participants. The evaluation found that knowledge of DS, confidence in communicating with parents and in delivering a diagnosis of DS significantly increased after attending. Some evidence of applying knowledge in the workplace was identified, however training such as 'Tell it Right' must become embedded in mandatory professional education if widespread improvements in parent experience are to be achieved.

Key words:

Down syndrome; training; evaluation

Key Points:

- Many parents who receive a diagnosis of Down syndrome report dissatisfaction with their care during this time. The UK Down's syndrome Association has developed the "Tell it right, Start it Right" training to improve knowledge, understanding and clinical practice in this area.
- An evaluation of the training was conducted using the Kirkpatrick four level model, which is an established approach to measuring the impact of training
- Surveys delivered at three time points established that attending "Tell it right, Start it Right" was associated with increased knowledge about DS, increased confidence in communicating with parents, and some evidence of behaviour change in practice.
- Non-mandatory training is limited in reach and impact, therefore training in how to communicate about DS and deliver a diagnosis must become to become embedded in the

education of all relevant health professionals if sustained improvements in parental experience are to be achieved.

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INTRODUCTION

Down syndrome (DS) is one of the most common and recognisable conditions associated with learning disability and approximately 2.7 per 1,000 pregnancies are affected (Morris and Springett 2014). Many parents reflect back on the experience of receiving a diagnosis of DS and the care around that time with emotion (Skotko 2005). In some cases, especially when they choose to continue the pregnancy or receive the diagnosis after their baby is born, parents experience anger and dissatisfaction with the care they receive (Edwins 2000;Lalor, Devane and Begley 2007;Mills et al. 2015;Sooben 2010). Sources of this dissatisfaction include perceived staff insensitivity, a feeling of information being withheld by midwives, being given the diagnosis when a partner is not present, and a lack of accurate up-to-date information (Edwins 2000;Lalor et al. 2007;Sooben 2010;Gammons, Sooben and Heslam 2010;Mills et al. 2015). Some parents particularly dislike the framing of the diagnosis as ‘breaking bad news’(Reynolds 2003). Although there is some literature on good practice, most health professionals receive no formal training on how to communicate with parents about DS or deliver a diagnosis (Skotko, Capone and Kishnani 2009;Groot-van der Mooren et al. 2014;Puri and Morris 2015).

In England and Wales all pregnant women are offered prenatal screening tests for DS through the NHS. Midwives are tasked with providing ‘balanced and accurate information about DS’ to enable pregnant women to make informed choices about screening and subsequent decisions, including continuation or termination of pregnancy (NICE 2008). Despite this, midwives may not always feel confident or comfortable in talking to parents about disability (Ahmed, Bryant and Cole 2013). Clinicians can also find delivering a high risk result or a diagnosis of DS to parents as challenging (Skotko et al. 2009;Menezes et al. 2013). In response, the UK Down’s syndrome Association (DSA) has developed the “Tell it Right, Start It Right” training for health professionals. The objectives of the training are “*to ensure*

that health professionals have up to date, accurate and balanced information about living *with Down's syndrome*" and "improve the way that new parents are told that their baby has *Down's syndrome*" (Down's Syndrome Association 2015). The training is delivered by a DSA trainer with contributions from members of a local support organisation. The content and format of the training is provided in Table 1

To date, over 1,200 health professionals have attended the training and informal feedback collected by the DSA has been very positive. However, there has been no independent, formal evaluation of the training in terms of how it meets the objectives of health professionals and the services within which they are employed.

[Table 1 about here]

Aims and objectives of the study

This research independently evaluated the "Tell it Right, Start it Right" training delivered in 2014 to staff working in one NHS trust. We aimed to:

- 1) Identify the training objectives from the perspective of NHS services and staff.
- 2) Evaluate the training against these objectives using a validated training assessment model.

METHOD

Design

A repeated measures online survey was conducted at three time points: before training, immediately after training and two months after training. The surveys were constructed using Bristol Online Survey (BOS) software (Research IT University of Bristol).

Development of the survey

The surveys were developed using the well-established Kirkpatrick model of training evaluation (Kirkpatrick and Kirkpatrick 2006). The model distinguishes four levels of evaluation; (1) Reaction - trainees opinions about the training and their personal reactions to it, (2) Learning - increase in knowledge or skills as a result of the training, (3) Behaviour - the extent to which the trainees apply the learning and change their behaviour in the workplace and (4) Results - the extent to which all the above changes produce improvements for the organisation. In this study, the first three levels were assessed. The Kirkpatrick approach to measuring the impact of training has been used previously in relevant healthcare settings (Crofts et al. 2007; Lee, Allen and Daly 2012). Reviews using the model as an evaluation framework have found it to be useful in generating evidence on whether training is effective beyond individual staff attitudes and practices (Leslie et al. 2013; Smidt et al. 2009).

Implementing the Kirkpatrick model requires prior identification of the training objectives from the organisational perspective. Objectives were identified via telephone interviews with clinical leads from services to which the training would be of relevance: midwifery, neonatology, paediatrics, and genetic counselling. Clinical leads identified a range of learning objectives relevant to staff attending the training.

At each time point, the survey collected data relevant to the stage in the training process. Survey 1 captured objectives for attending the study day, experiences of communicating about DS and measured confidence in communicating about DS or delivering a diagnosis. Survey 2 assessed reactions to the training, whether previous objectives had been met, measured change in confidence, perceived increase in knowledge, and intention to use learning in practice. Survey 3 measured maintenance of confidence and assessed the

application of learning in practice. Table 2 gives examples of questions from each survey and their relationship to the Kirkpatrick model levels.

[Table 2 here]

Ethical approval

The main ethical issue concerned data protection associated with online collection of data on a sensitive topic. The research was approved by the School of Medicine Research Ethics Committee at the host institution (SoMREC/13/035).

Recruitment

The study day was advertised to staff via clinical leads in the services previously identified. Attendance was voluntary. The DSA did not charge to deliver the training although a nominal cost of £10 was charged to cover catering costs. The training was run at the collaborating University.

Delegates were invited to participate in the research using the email address they had provided at registration. It was emphasised that staff did not have to participate in the research to be able to attend. Two reminders were sent after each survey opened, and the surveys closed after 14 days. As an incentive, participants were informed that the local DS parent support group would receive £1 for every survey completed.

Procedure

A survey 'front page' informed potential participants about the purpose and nature of the research. If delegates wanted to participate they selected 'Yes' in response to the statement "Having read the information provided, I agree to take part in this survey". This process was repeated for each survey. Participation was anonymous, however to enable repeated measures

analysis participants generated a personal identifier that used partial information from birth date and home postcode.

ANALYSIS

Survey data were downloaded from BOS via Excel into SPSS V22. Data analysis consisted mainly of frequencies. Paired t-tests were used to identify changes in confidence between Survey 1 and Survey 2. Responses to open ended questions were not analysed separately but used to illustrate quantitative findings.

RESULTS

Participants and response rate

Sixty-three people registered for the training day, of whom 42 (67%) completed Survey 1.

Fifty-six of those registered attended the day, of whom 38 (68%) completed Survey 2.

Twenty-three (41%) attendees subsequently completed Survey 3. The number of respondents for each survey by specialty is provided in Table 3. Across all surveys, time in clinical practice ranged from zero years (students) to 40 years.

[Table 3 here]

Clinical context and experience

In Survey 1, participants were asked in what situations they communicated information about DS: 73% used information when offering screening or diagnostic tests; 24% after a prenatal diagnosis of DS; 51% after a postnatal diagnosis and 46% in the community setting with families. Direct experience of delivering a high risk screening result or an actual diagnosis of DS was very limited. Three out of 24 staff working in antenatal services had communicated a

high risk screening result and two had delivered a prenatal diagnosis of DS: five participants (one midwife, four paediatricians) had delivered a postnatal diagnosis.

The most common source of information about DS was the NHS booklet “Screening Tests for You and Your Baby” (2012) (73%), followed by local resources (43%) and the DSA website (34%). Around 15% sourced information from medical textbooks or online equivalents.

Evaluation within the Kirkpatrick Model

Kirkpatrick Level 1 - Reaction

Table 4 shows the objectives for attending of those who completed Survey 1 (N=42) and Survey 2 (N=38) and whether or not these objectives were met. The results demonstrate a desire for information about DS itself as well as guidance on communicating with parents and delivering a diagnosis. In all cases over 80% of attendees reported their objectives had been met by the training.

[Table 4 here]

In Survey 2, all respondents agreed that they liked the training day, 95% agreed it was relevant to their clinical practice, 94% that it was a good use of their time and 94% would recommend the training to colleagues. The majority of qualitative comments were positive, for example;

“I benefitted from the training [which] facilitated considerable self-reflection on my personal practice.” (Paediatrician)

Overall, the contribution made by parents and a young person with DS was the most popular aspect of the training; for example;

“Parent input was powerful and [the] most important part.” (Role given as ‘other’)

Two participants felt that the parents did not represent families from economically disadvantaged backgrounds or where English was not the first spoken language. Nearly 40% of respondents to Survey 2 were unsure (36%) or disagreed (13%) that the information about DS was balanced. For example;

“I felt the information was very much [from] parents who had accepted and were coping with DS ... but not alluding to the fact that some families may be completely disrupted in this situation because the child has many time-consuming needs.”

(Screening co-ordinator)

A small number of participants felt the material delivered by the parents over-emphasised negative aspects of medical practice, for example;

“I did feel that midwives and others were given a bit of a bashing ... the health professionals point of view should be considered as we do not aim to give poor service to any women or their families” (Midwife)

This respondent commented that as a diagnosis of DS was such a rare event, ‘unintentional mistakes in terminology’ were probably to be expected ‘through lack of experience not lack of care’ (Midwife).

Kirkpatrick Level 2 - Learning

Knowledge

Knowledge was not assessed directly as the range of material covered was extensive and previous experience varied considerably across participants. Therefore self-reported knowledge increase was used as a proxy measure. Table 5 shows that most participants reported increasing their knowledge across all the areas measured.

Confidence

In those who completed both Surveys 1 and 2 (N=28) confidence significantly increased after training across the all the variables measured (see Table 6) with the exception of confidence in communicating with parents from a range of ethnic groups. Some participants identified areas where they still lacked confidence, for example;

“As it is not something I experience regularly in my practice I'm not confident in all areas of information giving and support - but I am now aware of where to find the information relating to DS.” (Midwife)

[Table 5 & 6 here]

Kirkpatrick Level 3 - Behaviour

All of Survey 2 respondents agreed that they would be able to apply the learning in their practice and would share knowledge with colleagues, for example;

“I intend to tell as many students as possible the things I learnt on the day. I really do think it should be part of the university course.” (Midwifery student)

All Survey 3 participants but one (N= 23) said they had shared what they had learned with their colleagues. The majority of these sharing scenarios were informal, for example, during a team meeting. Two paediatricians said they had delivered teaching to junior doctors and one respondent had given a presentation on service improvement to colleagues. One midwife and a neonatal nurse said they had created information resources for colleagues and parents based on materials from the training day.

Most of the Survey 3 respondents (n=14) said they had not had the opportunity to put their learning into practice, for example, because there had been ‘no babies with DS born in their

unit' or they had not been involved with expectant or new families. Of the nine who reported having had an opportunity to use the learning, one respondent had delivered a diagnosis of DS, and three had supported new parents. Prenatal screening consultations were included as examples in both 'yes' and 'no' opportunity categories. One midwife said she had used the learning to "discuss the combined screening for DS with pregnant women" whereas another said she had no opportunity as she had "no contact other than consent to screening".

DISCUSSION

The results of the evaluation show that staff attending the "Tell it Right, Start it Right" training increased their knowledge of DS and confidence in communicating about DS including at the time of diagnosis. There was also limited evidence of behaviour change in clinical practice. There were, however, some limitations to the study. Firstly, only one training event was evaluated and so the findings cannot be generalised to other events. The online survey could easily be adapted for other study days if it were possible to conduct a longer term evaluation in the future. Secondly, the number of attendees completing the final survey limited the generalisability of the findings related to 'Behaviour' level of the Kirkpatrick Model. It may be that those who had not changed their behaviour chose not to respond to Survey 3.

While the involvement of families with children with DS was generally considered the most important element of the training, some respondents perceived that the experience of having a child with DS was presented in an overly positive light. Health professionals tend to see families with a child with DS at times of stress or illness and so it may be hard to envisage what normal life is like outside these periods. In addition, professionals working within

prenatal testing pathways may see positive stories of affected children as a challenge to the value of their role. Parents who contribute to the “Tell it Right, Start it Right” training sessions are usually members of support groups and may have access to social activities and other resources in a way that does not reflect the experience of all families. Research shows that some parents do find it difficult to positively adapt to having a child with DS (Cuskelly, Hauser-Cram and Van Riper 2008). Involving people with lived experience of a disability who do not come through support groups is a challenge in both medical training and in research. It may be more realistic therefore, to balance the parenting scenarios using the research literature rather than trying to enlist parents with less positive experiences.

A perception that the training was biased against health professionals was also apparent in some of the survey responses. It may be that those parents motivated to be involved in the training were more likely to have had a negative experience at diagnosis and so wanted to ‘tell their story’ in the hope that this would change practice. Those who received good care may have been less motivated to talk about their experiences. Training should incorporate a more balanced range of experiences so that professionals learn from ‘good’ as well as ‘bad’ practice (Mills et al. 2015). Staff involved in delivering the news to parents or caring for them during this time may also be vulnerable to anxiety, and experience feelings that are difficult to deal with; thus appropriate training and support is essential if they are to meet the needs of the families they care for (Reynolds 2003).

Communicating with parents from minority ethnic groups was the only area in which no significant increase in confidence was identified. There are known cultural differences in attitudes towards learning disability and improving the understanding of these in health professionals would support communication to women and families from minority ethnic groups (Scior 2011; Bryant et al. 2011). The “Tell it Right, Start it Right” training does not

specifically address these issues and this study reveals a training need in terms of increasing staff knowledge on cultural and ethnic variations in response to learning disability.

Conclusions

The findings show that opportunities for learning ‘on the job’ how to communicate a diagnosis of DS or to care for parents in this situation are often limited. This is not acceptable, given the enduring impact on parents who receive an inappropriately delivered diagnosis (Skotko 2005). While this study demonstrated personal benefits in attending the training the “Tell it Right, Start it Right” initiative is currently limited in its reach and impact. A high turn-over of staff in some key specialties can also mean that knowledge gained by an individual at one training event is quickly lost at a service level.

This study also demonstrated that there is a demand for ‘experience led’ training about Down syndrome among midwives and other health professionals that is not met by mandatory education. The main recommendation of this study is therefore, that training in how to communicate about DS and deliver a diagnosis, must become to become embedded in the education of all health professionals working in midwifery, paediatrics and neonatology. An essential ingredient of this training is the inclusion of the perspectives of people with DS and their families. Without this, sustained improvements in parental experience during this sensitive and crucial period are unlikely to be achieved.

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Table 1. Content and delivery format of the ‘Tell it Right, Start it Right’ study day

	Section	Content	Format
1	The DSA ‘Tell it Right Survey’ 2009	Results of the DSA survey of parent members’ experiences of screening, diagnosis and post-birth support	Trainer led lecture
2	Down syndrome	Information about the condition and associated health issues Areas of strength and difficulty Living with Down syndrome – from baby to adult: social and educational aspects	Interactive exercise Trainer led lecture
3	Parent’s perspectives:	Local parent support group sharing their experiences of the diagnosis and parenting their child	Series of short presentations with video
4	My life	A young person with Down syndrome sharing their life experiences	Presentation and video
5	Ensuring best practice	Participant clinical experiences and views on good and ‘bad’ practice	Group work and trainer led plenary discussion
6	Delivering the News	Information on how to how to deliver a diagnosis (pre and post-natal) sensitively and appropriately.	Trainer led lecture linked to DSA ‘Top Ten Tips’ material

Table 2: Examples of questions and relationship to the Kirkpatrick Model

Model Level	Example questions	Measure	Survey number
1. Reaction	The training day was relevant to my practice The training day met my [named] objectives	Five-point categorical scale (Strongly Agree to Strongly Disagree)	2
2. Learning (Knowledge)	I have increased my knowledge of the experience of being a parent of a child with DS I learned important information about good practice in delivering a diagnosis of DS	As above	2
2. Learning (Confidence)	I am confident about providing information about DS to women and parents I am confident about how to deliver a diagnosis of DS to parents	As above	1, 2 & 3
3. Behaviour	I have had the opportunity to use the knowledge and skills I gained during the training I have shared the information I gained with my colleagues	Yes/No plus qualitative response	3

Table 3: Number of respondents for each survey by specialty

Speciality	Survey 1	Survey 2	Survey 3
Midwifery	20	22*	14
Neonatology	7	5	4
Paediatrics	5	4	2
General Practice	3	2	1
Audiology	2	0	0
Health screening co-ordinator	1	1	0
Health visiting	1	1	1
Obstetrics	1	1	0
Radiology	1	1	0
'Other'	1	1	1
Total	42	38	23

*Some student midwives did not have the opportunity to complete Survey 1 as they enrolled on the day of the training.

Table 4: Participant objectives for attending and whether or not objectives were met

Objective	N having objective (%) Survey 1 N = 42	N having objective (%) Survey 2 N = 38	Objective met? (Survey 2)		
			Agree	Unsure	Disagree
To learn about parent’s experiences of having a child with DS	39 (93%)	35 (93%)	35 (100%)	-	-
To learn about parent’s experiences of receiving a diagnosis of DS	38 (90%)	34 (90%)	34 (100%)	-	-
To learn more about DS across the lifespan	35 (83%)	27 (71%)	23 (85%)	2 (7.5%)	2 (7.5%)
To improve communication with expectant parents or parents with children with DS	32 (76%)	27(71%)	26 (97%)	1 (3%)	-
To learn more about good practice in delivering a diagnosis of DS	31(74%)	27 (71%)	26(97%)	-	1 (3%)
To obtain more information to support pregnant women considering prenatal screening or diagnostic testing	29 (69%)	24 (63%)	20 (82%)	1(4%)	3(14%)

Table 5: Survey 2: Perceived improvements in knowledge (N=38)

Item	Strongly agree/agree n (%)	Not sure n (%)	Disagree/ Strongly disagree n (%)
I have increased my knowledge of how DS can affect the individual	34(89%)	3(8%)	1(3%)
I have increased my knowledge of a how a child with DS can affect a family	37(97%)	1(3%)	-
I have increased my knowledge of the experience of being a parent of a child with DS	38(100%)	-	-
I have increased my knowledge of the common health issues associated with DS	27(71%)	3(8%)	8(21%)
I learned important information about the experience of receiving a diagnosis of DS	38(100%)	-	-
I learned important information about good practice in delivering a diagnosis of DS	38(100%)	-	-

Table 6: Change in confidence for participants completing both surveys 1 and 2*

Item	Before (M, sd)	After (M, sd)	t, df	P value
I am confident about providing information about DS to women and parents (N=28)	3.21 (.88)	3.82 (.72)	-3.01,27	.006
I am confident about how to deliver a diagnosis of DS to parents (N=22)	2.27 (1.12)	3.32 (.78)	-5.46,21	0.00
I am confident about how to support expectant parents of a baby with DS (N=24)	2.75 (.85)	4.13 (.11)	-6.95, 23	0.00
I am confident about how to support parents of a new baby with DS (N=25)	3.00 (.82)	4.16 (.55)	-6.46,24	0.00
I am confident communicating about DS to women and parents from a range of ethnic groups (N=28)	2.93 (.72)	3.39 (.69)	-2.67,27	0.13
I am confident in where to find local and national information and advice about DS (N =28)	3.68 (.82)	4.61 (.50)	-5.02,27	0.00

*n varies due to some questions not being applicable to all participants