

SurvivorScotland and Talking Mats: Supporting people with learning disability to disclose issues of concern



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Background

In recent years there has been growing concern regarding adults who may be at increased risk of abuse either through their health condition, disability or due to the support they require to live their lives. It is known that poor communication is a particularly high risk factor in terms of increased risk of harm; Burke et al (1988) highlights the particular challenges faced by people with communication difficulties in recognising and reporting abuse particularly because they lack understanding about the nature of abuse and partly because they do not have the language and communication skills to report issues of concern.

Sobsey (1994) states that people with communication disabilities are two to six times more likely to experience physical, mental and sexual abuse as a result of their inability to communicate effectively.

Abuse of people with learning disability is recognised as a major problem. There have been numerous investigations and high profile cases which have highlighted the seriousness of this issue. Gravell 2012 in her recent study, Cruelty and Loneliness found that of the sixty seven people with Learning Disability interviewed sixty two had experienced some form of harassment, abuse and related crime.

In 2005 the Scottish Government launched the National Strategy for Survivors of Childhood Abuse, Survivor Scotland. The aim of the Strategy is to raise awareness, improve support services and enhance the wellbeing of survivors of childhood abuse. One of the priority areas of the Strategy is for people with a learning disability. The recent review Scottish Government review (2013) 'Keys to Life' still highlights the significant health inequalities and much reduced life span faced by people with a Learning disability. A significant theme in that review was to highlight the need to shift the culture and keep people with learning disability safe.

Previous Projects

6 Dimension Cards

SurvivorScotland commissioned a Data Collection Project in 2010 to trial a resource to facilitate disclosure for women with histories of childhood sexual abuse attending a gynaecological clinic in NHS Fife.

The project used a set of cards, termed 6D cards which had statements about health, wellbeing and previous life history. Patients were asked to select cards relevant to them and hand them to staff during their appointment. The study found that patients who elected to use the cards raised issues of childhood trauma during their consultation, where previously they had not. The full research report and user friendly booklet Helping Patients to Talk about Trauma can be accessed on the SurvivorScotland site www.survivorscotland.org.uk

6 Dimension Cards and Learning Disability

Following this study staff working in Learning Disability and Speech and Language in NHS Fife recognised that the cards may have application to adults with learning disability but would require further adaption, in terms of the language used and the levels of literacy required. Visual images would also be required and Change pictures were utilised. The aim of the project was to explore whether these adapted cards could help people with a learning

disability talk about any traumatic experience they may have experienced. www.changepeople.co.uk .

The project was led by Susan Gowland, Speech & Language Therapist, NHS Fife. It was trialled and evaluated by members of the multi-disciplinary Community Learning Disability Teams in Fife. The evaluation found that the cards were well-received by staff and service users involved in the trial. Using the cards enabled staff to gain a greater insight into the patient's perspective; informing them of them of the individual's priorities and highlighted issues that should be raised at care meetings. The cards were rated as being accessible and easy to understand for a range of clients with mild to moderate learning disabilities. It was recognised however that individuals with more severe learning disabilities and cognitive impairments would require a more structured framework to extend the effectiveness of the resource.

6 Dimension Cards, Learning Disability and Talking Mats: Staff training

Incorporating the 6D cards to Talking Mats was identified as the logical next stage of development of the project.

Talking Mats

Talking Mats is a low tech communication framework originally developed at Stirling University to support people with communication impairment and is now used in many different countries throughout the world. Talking Mats is an established communication framework with a strong research evidence base (Murphy and Cameron 2008) .The framework uses a mat with picture symbols attached as the basis for communication. It is designed to help people with communication difficulties:

- Consider and think about issues discussed with them
- Provide them with a way to effectively express their opinions

Talking Mats can help people arrive at a decision by:

- providing a structure where information is presented in small chunks supported by symbols
- it gives people time and space to think about information
- say what they feel in a visual way that can be easily recorded
- take account of all additional non-verbal and verbal comment

Talking Mats are designed to help those with communication difficulties express their views, however, not everyone will benefit from using a Talking Mat as it requires a certain level of symbolic understanding .It is also a visual system so someone with a severe visual impairment is unlikely to be able to use it.

NHS Fife Project

Susan, the project leader, undertook Talking Mats 'train the trainer' to enable her to train staff working in Fife in the TM Framework . Twenty staff were trained, predominantly nurses and Speech and Language Therapists This project was evaluated and report compiled by Susan (2012).

Overall Susan found that people with a learning disability when using Talking Mats showed increased engagement, understanding and expression and that correspondingly staff's understanding of what was being said by the people with learning disability was increased.

Recommendations from this work included:

- Training in Talking Mats is crucial to effective use
- Staff require additional training in child sexual abuse, dealing with disclosure and learning disability to increase their confidence in exploring the subject
- Redesign of the cards would improve the effectiveness of the Talking Mats framework

Current Project: SurvivorScotland and Talking Mats

SurvivorScotland commissioned Talking Mats to extend the work of the 6D project by addressing the above recommendations and trialing the resource in other areas of Scotland through an organised training program. It was agreed that training in CSA was critical therefore additional input was sought from Kingdom Abuse Survivors Project.

Redesign of Talking Mats Symbol Set

Further discussion with Susan Gowland defined the issues that needed to be addressed on the redesign of the Talking Mats, namely;

- The need to reduce the overall number of symbols used
- The need to integrate cards which might support disclosure into existing topics and not have it as a topic on its own
- Support staff to understand the relative impact of cognitive difficulties and identify who can and who cannot use Talking Mats effectively
- Support staff to recognise the language demands of topics that would be discussed and to be confident to know which topics involved more abstract concepts

Project Plan

Development of the SurvivorScotland Talking Mat

A development meeting was held in January 2013 with representatives from Survivor Scotland , Cornerstone, Kingdom Abuse Survivors Project, NHS Fife, Scottish Government and Talking Mats .

During the meeting the following process was adopted :

1. Each existing 6D card option was read out and put onto a mind map.
2. The options were themed and duplicates identified. At this point the language was simplified and the implications of the options, in terms of identifying indicators of possible CSA discussed.
3. Through this process three main themes were identified and these became the topics for the revised Talking Mats :
 - Health and Wellbeing,
 - Meaningful Relationships
 - Thoughts and Feelings

A maximum of fifteen symbols a topic was agreed.

4. There was discussion about the Top Scale for the Talking Mats as it was recognised that thoughts and feelings is more abstract and that it would be difficult to find a Talking Mats Top Scale that could work across all three topics.

Change symbols

In addition we agreed we would continue with the Change images. Change images had been used in the previous project and this would provide continuity. Considerable liaison was required to develop the images and this proved to be challenging as timescales were difficult and also the images for Talking Mats require to be as neutral as possible so that individuals can express either a negative or positive view. Unfortunately there was no scope for a further face to face development meeting which meant the development process was not as straightforward as it could have been. Examples of the symbols are found on Appendix 1.

Training Outline

Two training courses were run, each course consisting of two days, with staff expected to implement and use the Talking Mats resource in between the courses. Staff were given training in Talking Mats and in supporting an individual through disclosure.

This model of training staff is one where staff are expected to be highly reflective, both in terms of their personal communication and interaction style, but also in terms of how they listen to people and build trust to allow people with communication difficulties to express potential concerns. Participants were also expected to make a short film clip of themselves using Talking Mats.

A one day course was held for staff already trained in Talking Mats. This training focused on supporting disclosure and training in the specific TM resource. Course capacity for the three trainings was for forty four people in total.

Training

The training was planned to run March to May 2013 . Participants were sought through the Scottish Government Equally Well Network and through Talking Mats Limited networks.

Two courses were run in Stirling and one in Glasgow. In total fifty four people were offered places, seven did not attend. Seven people attended course One but could not attend course Two.

Profession	Participants
Advocacy	2
Gynaecology	1
Nursing	12
Occupational Therapy	3
Psychology	1
Psychiatry	1
Social work	3
Speech and Language Therapy	12
Volunteer	1
Total	36

The geographical spread also covered urban to rural though by no means the whole of Scotland . The greatest number came from Greater Glasgow.

NHS area	Participants
Ayrshire and Arran	3
Borders	4
Fife	1
Forth Valley	1
Greater Glasgow	13
Highlands	5
Lothian	3
Lanarkshire	2
Tayside	2
Western Isles	2
Total	36

The feedback immediately following the training was extremely positive and reflected that participants had had the space to think about the issues and think about how they could support clients with communication disabilities to disclose and discuss issue of concern.

'I have learnt ... about the importance of giving someone with LD an opportunity to communicate about difficult subjects It has made me think about ... working outside my comfort zone & looking for subtle opportunities to communicate and explore issues.

Presenters ... very friendly, open, good at listening to attendees opinions and feedback'

'Talking Mats used in this area is long overdue. I can think of numerous clients I have worked with in the past who would have benefitted – needs to be rolled out.'

'Powerful exercise with 'Molly' and all the coats and realising it is not necessary that you will have the answers and you don't need to know the exact questions to ask'.

'This course had made me hopeful for the future in terms of supporting survivors in a meaningful way.'

'Really interesting and thought provoking – will definitely try it with some of my clients and give feedback!'

Feedback immediately post-course is not the same as longer term impact and because of the topic not all participants had had the time to use the SurvivorScotland set in practice. It was decided to extend the evaluation period for a further four months and a Survey Monkey questionnaire was set up to allow for longer term responses. Twenty four out of the thirty six people who completed the course responded to the survey.

Evaluation

Description of the client group participants worked with

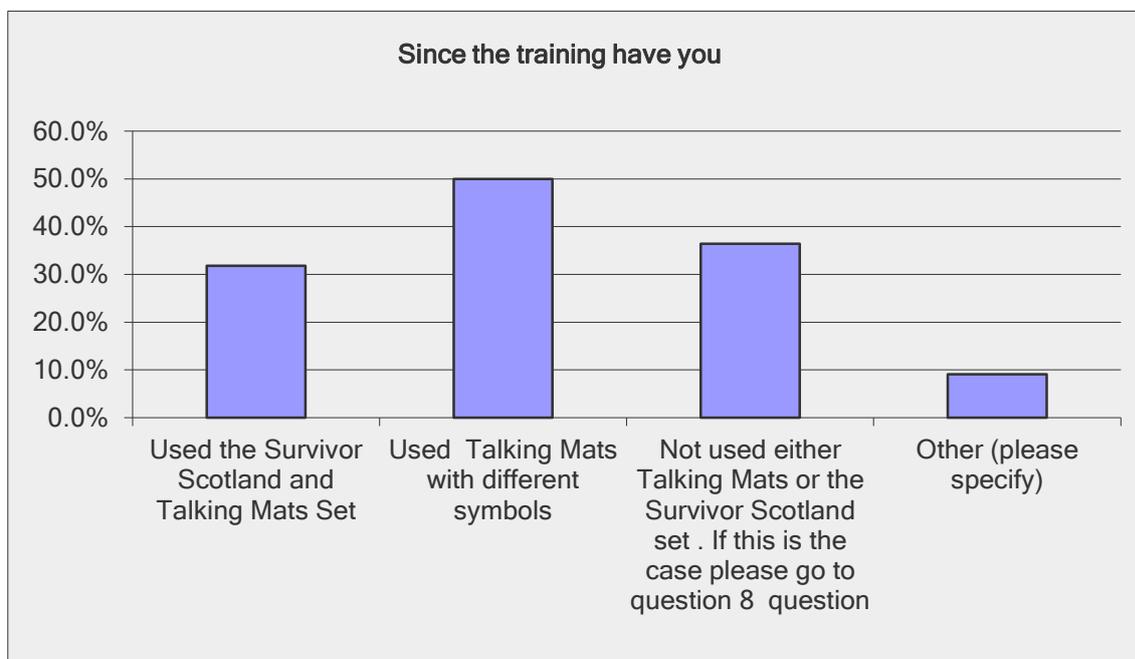
The client group that participants worked with all had learning disability and different levels of understanding and communication. Specific difficulties highlighted included difficulties initiating discussions, poor self-awareness, a tendency to react in the moment with little

understanding of consequence, poor understanding of time. In addition, a significant number of participants worked with people who had a diagnosis of autistic spectrum disorder and or a range of comorbid mental health and or other health conditions e.g. epilepsy and physical disability. The range of cognitive ability was reported as being highly variable ranging from being completely non-verbal with only a basic understanding of language (both spoken and written), operating at an object or symbolic level and limited attention, to the higher-functioning verbal clients who are able to hold a meaningful conversation. Some commented that disclosure type work tends to be with this latter group because of the inherent difficulties in consultation with people with more severe communication.

Use of the Resource

32% had used the SurvivorScotland set and Talking Mats set and 50% had used Talking Mats with a different symbol set which meant 18% had not used them since the training. No one expanded on why they had used a different symbol sets. Some people commented that they were planning to use them just had not the opportunity yet. Another commented on the SurvivorScotland symbols for the client she worked with.

'The images appeared to be too complex for one specific client. She appeared distracted by the specific detail and was unable to consistently identify the correct meaning represented by some of the symbols.' Another person commented *'that the pictures could be clearer and more colourful'*. However others said *'I had thought that some of the black and white symbols would have been difficult for some of my clients to understand, but they were all well used to using Talking Mats and just took the symbol and made it what their understanding of it was'* and *'I thought they worked well - some of my clients interpreted the concept differently to others, but in the main, they were well received and gained information that I may not otherwise have got'*

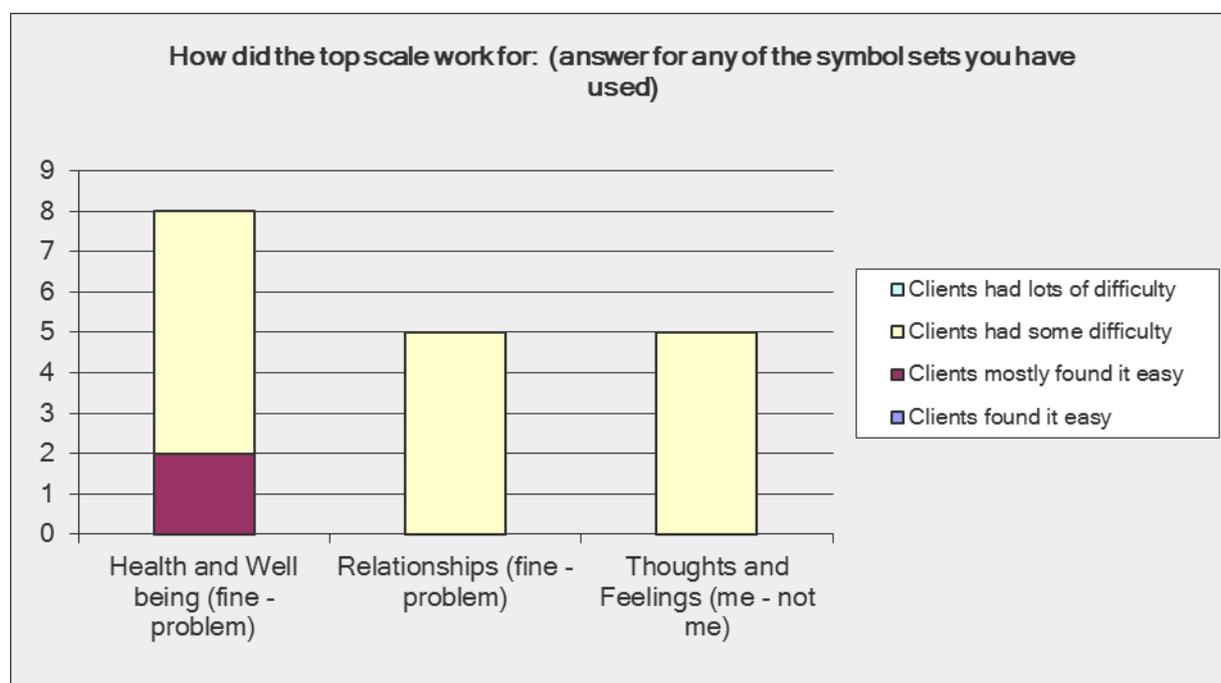


Analysis of Topic sets

Of the participants who had used the SurvivorScotland set the most common set to be used was Health and wellbeing . This set is the most 'concrete ' i.e. the options in the topics have a high degree of iconicity . Thoughts and feelings is the most abstract topic and requires participants to use executive function skills of planning and judgement and this was the least used topic .

Ease of the Top Scale

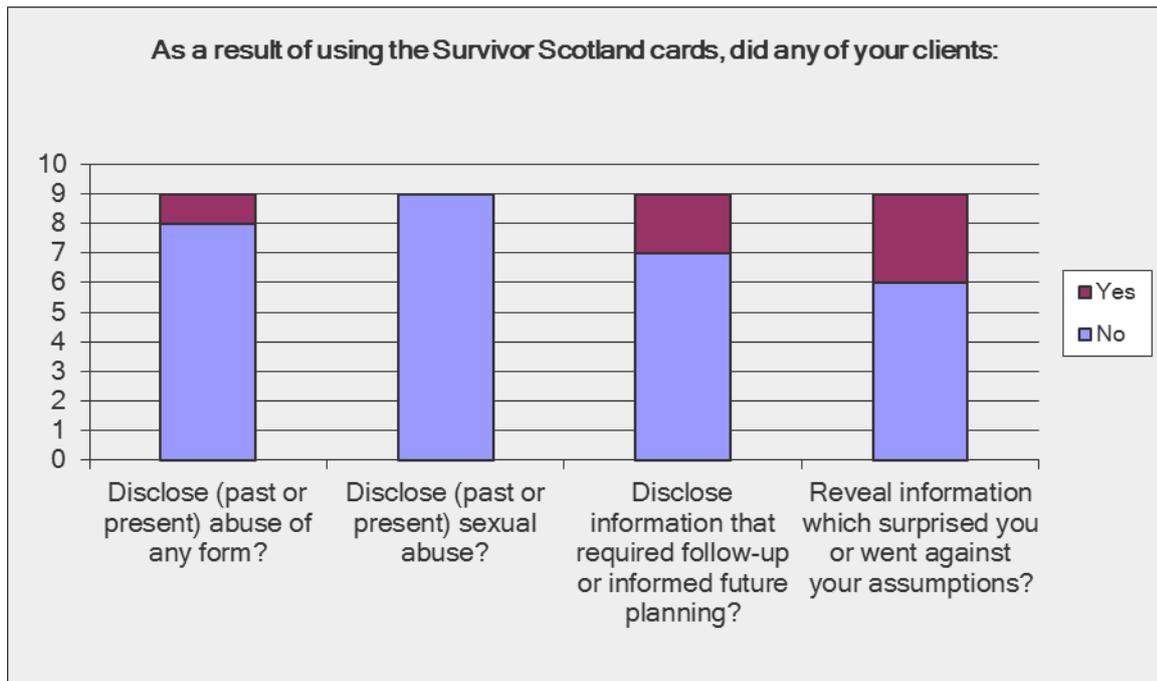
The challenge of the top scale is that you are asking about a client's health and wellbeing set against what the client knows is fine or a problem in general rather than for them specifically. One participant illustrated this difficulty by commenting e.g *'when asked about smoking and drinking alcohol. One client who didn't smoke or drink wanted to put it under thumbs down symbol indicating that it was a problem for some people '*



Disclosure

In the course of this evaluation one person made a disclosure that required further support and follow up. One participant commented that about *'Information given about events some time ago, client still confused and upset about it. This was quite an able individual who could verbalise how she felt. However Talking Mats symbols gave focus to particular issues.'*

Other examples provided were issues were raised, was mental health, suicidal thoughts and family relationships. Another participant commented that although no issues of concern had risen in the discussions she had with her client, she was able to support another member of staff *'I was recently able to offer support and advice to a colleague who's client has only just disclosed childhood abuse.'*

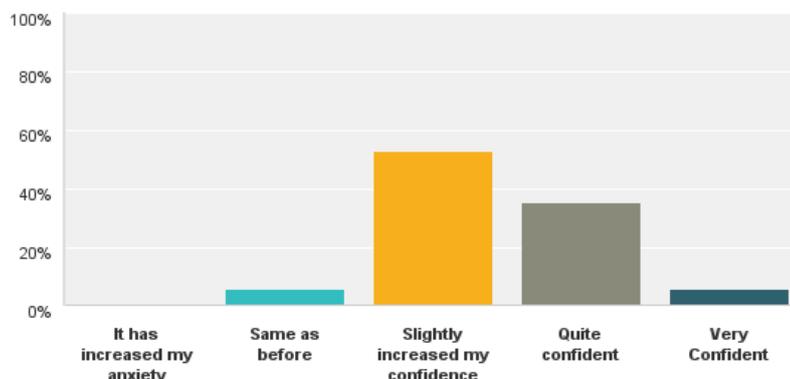


One participant contacted the office directly after the survey had closed to discuss use of the Talking Mats SurvivorScotland set. She had used the thoughts and feelings topic set with a lady with a learning disability. These cards had enabled this lady to disclose a history of CSA. The participants view was that *'the cards filter things in a way that I had not seen before and enabled my client to let go and talk about herself'*. This was a significant disclosure and enabled the participant to understand her client and the pressure she was under to a much greater degree than she had before. She is currently seeking on-going support for the individual.

Developing confidence

Q11 As a result of the training how would you describe your confidence in being able to hear and listen to disclosure and implement the next steps to support the individual

Answered: 17 Skipped: 7



During the course there was significant concern expressed over supporting individuals who disclosed a history of abuse. Whilst the course has increased people's confidence, it is an area that experience, reflection and a supportive working environment will be the factor that shifts professionals confidence level in the long term. More detailed comments reflected some significant shifts in levels of awareness and confidence that reflect the varying level of work and life experience that participants came to the course with

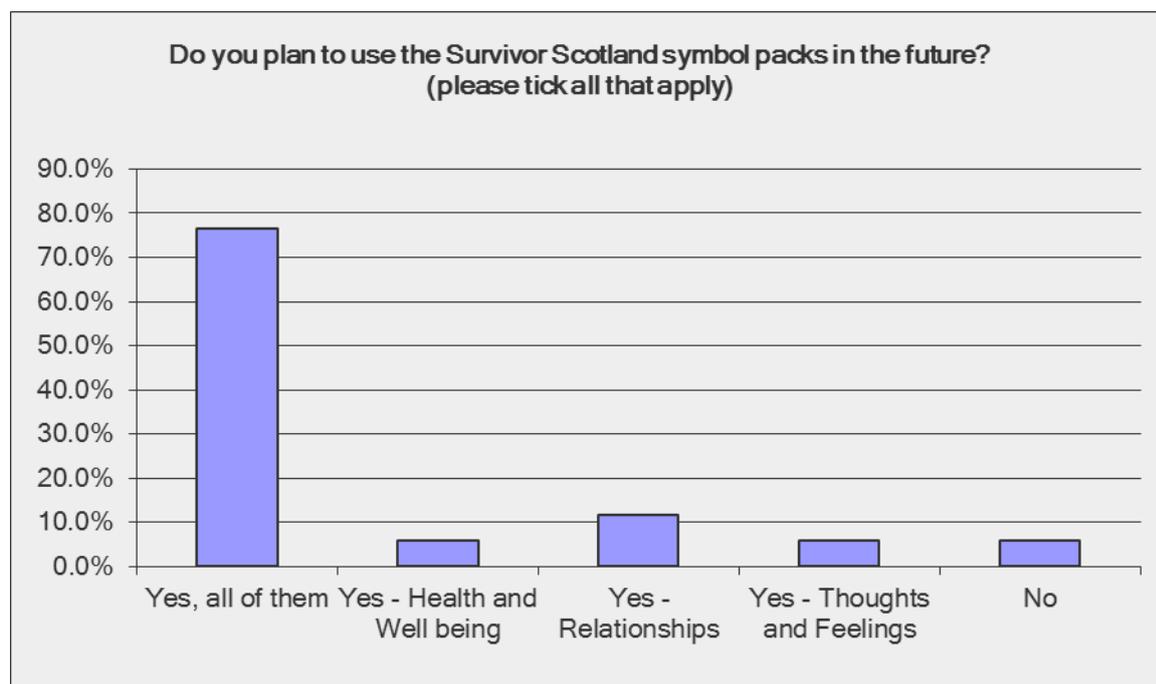
'I felt more confident to ask if someone had been abused. This was due to the role play that KASP done.'

'The training did help me to understand the impact that abuse can have on an individual, I did not appreciate this before. I will consider more how behaviours that clients with LD display could be related to abuse in their past or present. I still feel I would need support in supporting people with an LD to disclose issue of concern.'

'I feel that the training greatly increased my awareness of my responsibilities with regards to disclosure and how to support my client's in expressing themselves.'

'I feel that the main thing for me is that although I may feel uncomfortable inside when someone is talking about their experiences, I need to encourage this and not show any behaviours to indicate my upset'

Future Use



The majority felt that they would use the SurvivorScotland Talking Mats symbols in the future. Several felt that there was a need for on-going support as this would allow for continued development:

'It may be useful to have future feedback sessions/blog with participants of the training who have had more time to use the symbols with their clients. The training itself was great, and allowed us to experience how complex the issues are and the barriers we might face with

our clients in using the symbol cards. Hopefully these can be worked through as we increase our use of the symbol cards and put forward ideas for their development'

Local networks were also mentioned as a way of building and keeping support

'It would be useful have wee groups of people in your geographical area that you could meet with to problem solve any issues that come up.

Another participant commented that she had difficulty in her teams because of internal tension about perceived roles which she found frustrating.

'I have faced some difficulties using the pack fully as colleagues from other disciplines may feel it is stepping on their toes. By this I mean the nurses usually take the lead on sexual health and behaviour whilst the speech and language therapists lead on communication type intervention. There have been slightly awkward moments when I have been providing information about the project to the wider team.

This person also went on to say that she had been asked not to use the pack because of fears of contamination of evidence. This suggests there need to be a wider discussion with social work and health service managers and the police around policy, strategy and practice for interviewing people with communication disability.

I have a client who disclosed a sexual assault to me during the my normal work and my manger asked me not to use the pack as it would potentially contaminate the evidence – the police conducted the interview but it took three hours and was very stressful for my client'

One participant summed up their plans for the future by describing her proposed work with one client which sums up the challenges practitioners have in making sure they have the skills and resources to make sure they can the voice of people who for a whole host of reasons have difficulty expressing their views.

'I have planned to offer Talking Mats sessions to a client who has difficulty making choices and decisions regarding his health care. The client is very easily influenced by others due to avoiding conflict/ tendency to agree with, and want to please, others. These difficulties inevitably cause him a great deal of stress and anxiety (trying to please everyone) and can prevent him from being involved in, or accessing, necessary health care.

It is hoped that by helping him identify his concerns and communicate his preferences necessary adjustments can be made to improve his physical and mental health, therefore quality of life. Talking mats appears to offer a non-threatening environment for clients to express their true feelings, which should be ideally suited to this client. Talking mats has so much potential to be transferred into many areas.

I am already in the process of developing it in my own locality. From an abuse perspective, I can see the above symbol sets (health and wellbeing, relationships and thoughts and feelings) being a very effective, yet discreet, tool for identifying needs/ concerns and offering appropriate person-centred support. The Talking Mats/ survivor training has been invaluable to my future practice and improving support/ services for people with learning disabilities.'

Summary

There has been considerable progress to the lives of people with learning disability since the publication of the national strategy in 2000 Same as You. The Scottish Government review (2013) 'Keys to Life' further highlights the significant health inequalities and reduced life span faced by people with a learning disability

This project achieved the redesign and trial of the 6D Project into a SurvivorScotland, Talking Mats resource. This resource supports people with a learning disability to think about their health and wellbeing and express areas of concern including potential disclosure of abuse. The project could not have succeeded without the significant work that had already been undertaken in NHS Fife and the funding and support from Scottish Government Strategy, SurvivorScotland.

Training was key to the success of project, both in terms of understanding the use and potential of Talking Mats, but also in addressing participants' anxiety of supporting disclosures of abuse. The participants that were involved have an on-going resource that they can continue to use within their practice. Thirty six people from ten different health board areas in Scotland have completed the training. Participants commented on the need for on-going support and ways of sharing experiences and practice development

However this is still a relatively small group and there needs to be further discussion about how this work can be extended. The resource would benefit from being adapted further through reflection from applying and using in practice.

Issues arose in this evaluation around the images. There was mixed opinion about the images used - the Thoughts and Feeling topic remains the more challenging section. No simple solution has emerged as this is a topic that the experts in CSA feel is important to be included and indeed it proved to be a very salient topic for the CSA that was disclosed.

Reflection on this topic requires a high cognitive load, ability to deal with abstract concepts and flexibility of thought so it may not be helpful for all people with a learning disability. Participants commented on the need for on-going support and ways of sharing experiences and practice development. More learning opportunities are required to extend the use of the resource to more practitioners which would hopefully increase peer and management support and confidence in the cards.

This is a complex area of work and will require on-going work and service development. The complexities arise both from the topic which often raises anxiety in staff and the group that is being targeted, i.e. people with a learning disability. They are not a homogenous group and have a wide range of needs and living situations. It will not be suitable for every person with a learning disability, however use of this resource does enable more people with a learning disability to reflect and communicate their thoughts on their health and wellbeing as it provides a 'scaffold' for their thinking: *'This is an excellent communication tool – the reason, it provides structure, control, indirect prompts for individuals to discuss personal and difficult topics in a safe context'*

References

Burke L et al (1998) Dealing with sexual abuse of adults with a developmental disability who also have impaired communication: supportive procedures for detection, disclosure and follow-up The Canadian Journal of Human Sexuality. Volume: 7. Issue: 1

Cameron and Place (2011) Final report Adult Protection Scotland Project (APP 2): You have to be told in a language you can understand what your rights are'.

Gowland (2012) Learning Disability Six Dimensions: a Communications resource for supporting people with Learning Disability with health consultations and disclosure of abuse NHS Fife

Gravell Carywn (2012) Loneliness and Cruelty Pub Lemos and Crane

Murphy J and Cameron L (2008) The Effectiveness of Talking Mats for People with Intellectual Disability British Journal of Learning Disability 36: 232-241

Neufeind and Hannah, Talking Openly: Using 6D Cards in clinical consultations to allow patients to talk about trauma.

Sobsey D(1994) Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance Paul H Brookes Publishers

Scottish Executive 2000: The Same As You

Scottish Government 2007: Communication Support Needs: A review

Scottish Government 2013 :Keys to Life

The Health and Social Care Information Centre (2012) Abuse of Vulnerable Adults in England 2010-11: Experimental Statistics Final Report

Appendix 1

Topics and examples of Symbols from the SurvivorScotland Talking Mats Images ©Change symbols

Health and Well Being

Fine (not a problem) – unsure – Problem

1. Sleeping
2. Eating
3. Smoking
4. Drinking
5. Exercise
6. Medication
7. Drugs
8. Going to doctors
9. Going to dentists
10. Being in pain
11. General health
12. Energy levels
13. Thoughts and feelings
14. Hurting myself



Meaningful Relationships

1. Family
2. Friends
3. Neighbours
4. Workmates
5. Staff
6. Partner
7. Fighting with people
8. Bullying
9. Someone hurting me
10. Being scared of someone
11. Cuddles and kisses
12. Having sex
13. People taking my money
14. People deciding things for me
15. People believing what I say
16. Trusting people



Thoughts and feelings

1. Sad
2. Lonely
3. Feeling up and down
4. Angry
5. Scared
6. Worried
7. Able to talk about myself
8. Thinking I am a bad person
9. Thinking about bad things that have happened
10. Missing people
11. Making my own choices
12. Getting all mixed up
13. Keeping a secret I don't like
14. Feeling ashamed
15. Feeling like I want to die

