

Creating a listening space for people with learning disabilities to think and share how their lives are going

# Funded by Scottish Government Keys to Life April 2017

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#### **Symbol Intellectual Property**

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#### **Talking Mats Limited**

Talking Mats Limited is a social enterprise that spun out of University of Stirling in 2011. Its vision is to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them.







## **Executive Summary**

The Keeping Safe project has resulted in a cost effective, sustainable way to support people with a learning disability in Scotland to think about their lives and express concerns. This project was funded by Scottish Government.

This project started in April 2014, as an extension of an earlier project involving Survivor Scotland, NHS Fife and KASP <sup>1</sup>. The background, methods used, and outcomes are detailed in the report submitted to the Government in March 2016 <sup>2</sup> The aim of this last part of the project was to focus on the sustainability of the training and the resource, the dissemination of the information, and the cost benefit of its use. An overview is provided in appendix 1.

Sustainability of the projects has been achieved by

- Continuing to develop access to the resource and provide training to allow staff to
  use in their work settings. This was done through providing training courses (186
  people) and through the development of a train the trainer scheme (363 people)
- Developing further resources that will support use of the resource when project funding ends including videos and accompanying booklet
- Integrating the Keeping Safe resource into the existing Talking Mats resources and train the trainer schemes so they will still be available once the project is finished
- Continued marketing of the resource using existing Talking Mats networks and website

A cost benefit analysis was carried out using the stories submitted to the project .There is a significant financial advantage to services using Talking Mats. For each pound invested in the Keeping Safe training there is a potential saving to public services £23.00. In learning disability services it is easy for costs to accelerate quickly particularly if an emergency placement is required for if services don't respond effectively challenging behaviours can escalate and then there is a potential risk of existing relationships and placements breaking down.

The different Keeping Safe projects has given valuable insight into the lives of people with a learning disabilty living in Scotland in 2015-2017. We are grateful to the Scottish Government for their commitment to this work, and to our trainers for continuing to disseminate the resource. We are glad that together we have developed a framework that supports staff to really listen to the concerns of people with a learning disability and supports people with a learning disability to reflect on their lives and articulate views and concerns. We are hopeful that through this process they can identify the next steps to improve the quality of their lives and help address long standing inequalities.

<sup>1</sup> http://www.talkingmats.com/wp-content/uploads/2013/08/Talking-Mats-and-Survivor-Scotland-final-Report.pdf

http://www.talkingmats.com/wp-content/uploads/2016/07/160512-Keeping-Safe-report-2013-2016.pdf

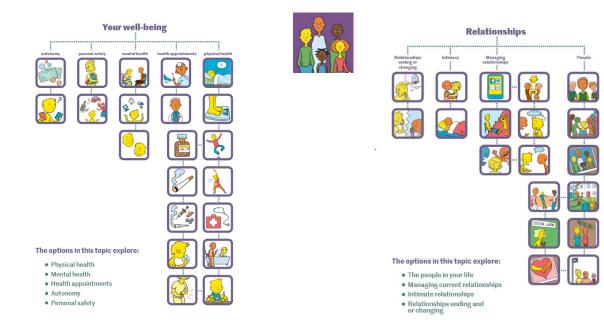




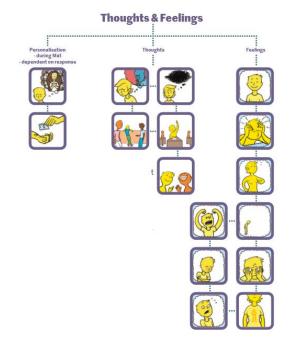


## The Keeping Safe resource has 3 topics:









#### It also has:

- A Resource Book that explains how to use the resource and is illustrated with case examples
- A password protected vimeo account for people to see vidoes demonstraining use of the resource







## **Summary of Training**

As of March 2017 **549 people** who work with adults with a learning disability have the resource and have been trained to use it.

#### **Courses Held by Talking Mats**

Health authority	Dates	Number of courses	Number attended
Borders	10/12//14	2	18
	08/03/16		
Inverness	18/12/14	1	9
Glasgow	26/05/15	1	13
Ayrshire and Arran	25/06/15	1	17
Stirling	22/01/15	4	63
	23/10/15		
	16/09/16		
	20/10/16		
Fife	19/02/15	2	24
Aberdeen	07/101/6	1	13
Dumfries	25/11/2016	1	15
Lothian	20/01/17	1	14
Total		14	186







## Range of professions trained (Talking Mats courses)

Social or Care support workers	36
Learning disabilities nurses	31
Social workers	28
SLTs	26
Psychologists	21
Day care officers	14
Advocates	10
Project Officers	3
Communications officers	2
Occupational Therapists	2
Health Facilitator	2
Trainers	2
Teachers at transition	2
Other	7
Student (LD team)-1	
Tenant and service users participation assistant-1	
Activity Scheme Co-Ordinator with disabilities team	
-1	
Positive Behaviour Support -1	
Team leader education-1	
SDS coordinator -1	
Training and voluntary coordinator -1	
Total	186







## **Courses held by accredited trainers**

	Number of courses	Number attended
Lothian	7	81
Lanarkshire	10	67
Glasgow	8	76
Ayrshire and Arran	3	24
Midlothian	1	6
Inverclyde	3	17
Borders	5	43
Argyll and Bute	1	4
Perth and Kinross	4	36
Fife (more figures to submit)	1	9
		363
	+ Trained by Talking Mats	186
Total as of 28/03/17		549 people trained

## **Keeping Safe accredited trainers**

Health Board area	Numbers	comments
Argyll and Bute	1	One left as post no longer funded
Lothian	5	
Greater Glasgow and Clyde	4	1 in training
Fife	2	
Ayrshire and Arran	1	
Lanarkshire	2	1 in training
Tayside	2	
Borders	1	1 more potential
Dumfries		1 in training
Forth Valley	1	







## **Cost Benefit Analysis**

A cost benefit analysis was carried out with the support of Inspiring Scotland. We had 100 impact stories from the project. These were reports that practitioners sent us when they used the resource in the field.

Cost-benefit analysis demonstrates the overall economic value of an intervention with numbers and evidence.

6 cases were chosen that represented a cross spectrum of people with learning disabilities in Scotland both in terms of living situations e.g. living at home, in supported settings and an inpatients facility. They were also chosen to represent the comorbid conditions that often coexist with learning disability e.g. autism, mental health and cerebral palsy.

#### **Process**

A calculation was done in terms of cost of the Talking Mats intervention and resulting actions.

An alternative scenario was created and tested with critical friends as to the likelihood of what might have happened without the Talking Mats intervention.

In both cases unless otherwise stated the primary source of financial information and the subsequent calculations was the is the Unit Costs of Health and Social Care produced by the Personal Social Services Research Unit (PSSRU) 2015/16. This contains detailed cost estimates for a range of services such as care placements, NHS services, social work, mental health, and some family interventions. For each service, a range of costs are presented including building and land costs, salaries and overheads.

This analysis can only be illustrative as assumptions are subjective.





**Cost Benefit Analysis** 

**Keeping Safe** 

**Example 1** 

Unless mentioned the data source used is the Personal Social Services Research 2015/16

#### A man with learning disability

- living in his family home
- very anxious because of impending job interview.
- Becomes physically ill with vomiting and stomach pain.
- unable to sleep.
- recent bereavements in the family.
- He found talking about himself and his feelings extremely difficult

#### What happened

A thoughts and feelings talking Mat was carried out by his advocacy worker. He said 'more in 30 min than he had done in years' and he expressed his anxieties and feelings of grief.



This was shared with the family who were understanding and wanted to support him. They had not understood the extent of his feelings of loss and sadness. It was agreed to stop the job search and allow him time and space to grieve. Physical symptoms slowly resolved.

#### Possible alternative scenario

His physical symptoms persisted

His support worker arranged a GP appointment. Cost based on a double GP appointment of 14 minutes each appointment with a support worker in attendance

He was prescribe d sleeping tablets



Non intervention			0
GP referral	0.48	385	184.8
Sleeping tablets	1	41.35	41.35
support to attend	2	35	70
			296.15

Total Cost of intervention was £271.60 with risk of long term dependency on drugs forming

#### Cost

Туре	hours	unit cost	total cost
Tm interview	0.5	35	17.5
ongoing support	2	35	7(
			87 1

Total

Cost of the Intervention £87.50





**Cost Benefit Analysis** 

**Keeping Safe** 

**Example 2** 

Unless mentioned the data source used is the Personal Social Services Research 2015/16

A woman with a diagnosis of Aspergers and generalised anxiety

- Living in her family home
- Referred to Occupational Therapist by her psychiatrist
- Withdrawing from all activities
- Becoming more dependant on family for activities of daily living which assessment showed were skills she had
- Finds it difficult to communicate her needs and express herself
- Could not think about future goals
- Becoming agitated when friends or family are talked about

#### What happened



A relationships talking Mat was carried out in which she identified

- Social media bullying
- Loss of contacts with school friends. She wanted to meet them but her level of anxiety linked to SM comments prevented her from doing this
- Discussion with Mum family wanted to support her in this
- Further Talking Mat to identify activities and interests that would help support engagement with friends
- Some ongoing support to family

#### Cost

**Total Cost £352** It may be that consideration will be given in the future to independent living the cost of planned independent living is generally less than if that occurs through planning than a through a crisis

#### Possible alternative scenario

- 1. She withdrew even further from all activities .
- 2. Her agitation persisted and became increasingly challenging
- 3. He family became exhausted and unable to support her
- A multi disciplinary meeting was called
- 5. Weekly support by challenging behaviour team was put in
- 6. A review meeting
- 7. A crisis occurred resulting in emergency hospital admission
- 8. Long term placement was found in care setting

multi agncy meeting	2	792	1584
increased community staff input	42	44	1848
emergency hosp admission	28	654	18312
	1		21744

**Cost** Total Cost of intervention is variable depending on scenarios occurred:

- 1-6 cost would be was £3432
- 1-7 cost would be £21744
- 8 would depend on care home but could reduce the cost on an going basis by £19,604 a year from high staff unit to lower staff unit. A placement post crisis is likely to be more costly and require a higher staff ratio





#### **Cost Benefit Analysis**

**Keeping Safe** 

Example 3

Tm interview further support

Unless mentioned the data source used is the Personal Social Services Research 2015/2016

# A man with learning disability, anxiety and a history of offending behaviour

- Residing in specialist inpatient facility for learning disability
- Has word finding difficulty and expression of views is difficult
- Direct 1:1 conversations and questioning can leads to increased pressure leading to worsening anxiety.



#### What happened

An initial 'Wellbeing talking Mat' was carried out in which he was able to express

- In hospital he did not have access to drugs or alcohol so they were not a current problem
- Stress was difficult as he often gets tongue tied
- He prefers others to make decision for him but that also makes him feel that he has less control
- · He finds it hard to talk about himself
- He was unsure about his weight and had no idea what a healthy weight would be for him
- He didn't like doctors
- Things going well included ;prescribed mediaction, eating, exercise, personal care
- He initiated a conversation on trust and that he does not feel staff trust him because of his history. They think he will reoffend

#### Action

The resource was helpful because it allowed the staff to see things from the patient's perspective and shifted their response to being more patient centred – explaining and supporting him in areas he had identified through the Mat.

	Tm interview	1	35	35
	hospital stay	388	330	128040
Cost				128075

#### Total Cost £ 128075

#### Possible alternative scenario

- That care continued without the person centred focus and knowledge of what patient was feeling about his inpatient support
- A study in Gothenburg identified that a patient focused approach as opposed to a more standard approach reduced inpatient hospital stays by 30% Ekman, A. Wolf, L.-E. Olsson, C. Taft, K. Dudas, M. Schaufelberger, K. Swedberg. Effects of personcentred care in patients with chronic heart failure: the PCC-HF study. European Heart Journal, 2011; DOI:

10.1093/eurheartj/ehr306
Not found comparable evidence in learning disability but have used this figure of 30% reduction as an assumption.

#### Cost

Hospital stay	554	330	182820
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Total cost £182820





#### **Cost Benefit Analysis**

**Keeping Safe** 

**Example 4** 

Unless mentioned the data source used is the Personal Social Services Research 2015/16

A man with autism who lives on his own with a support package

- Has high level of comprehension and very detailed interest in politics.
- On occasions he does not permit his support staff access to his flat.
- has difficulty processing information including filtering out what information is relevant and will include a lot of detail in his responses

#### What happened

An initial 'Relationships Mat' was carried out in which expressed

- concerns about some of his staff,
- he felt their behaviour to him was not always appropriate –he perceived them as nagging
- that he sometimes had concerns about when he was in the community about safety



#### **Action**

- Identified what staff support would be more helpful (including, the possible introduction of new staff to the team).
- It helped identify areas of staff practice that require development; working on how staff support and present tasks.
- Work on personal safety.

#### Cost

Туре	time	unit cost	total cost
Tm interview	1	55	55
further support	2	55	110
work with staff	4	55	220
total cost			385

#### Possible alternative scenario

- Three further visits where staff were refused entry
- Social work visit
- Man becoming increasingly withdrawn
- Multi agency visit to discuss concerns
- Further support to staff on how to support and present tasks



#### Cost

Potential costs			n
1 otential costs			0
3 failed visits of support staff to house	1.5	24	36
social work visit	3	55	165
multi agncy emergency meeting	2	687	1374
further work with staff re support	4	55	220
total cost			1795



**Cost Benefit Analysis** 

**Keeping Safe** 

**Example 5** 

Unless mentioned the data source used is the Personal Social Services Research 2015/16

# Keeping Safe



A young woman with learning disability who is in process of transitioning from family home

- Family very supportive of the move They are thinking of her future and want to see her in independent living
- Low mood



#### What happened

An initial 'thoughts and feelings Mat' was carried out in which expressed

- How worried she was about the move
- That she felt she was letting her family down by not being brave,
- Everyone was telling her how good the move was and she could not say what she felt



#### Action

- Arranged a doctors appointment where they received support for their low mood (in the end they take not opt for medication as mood improved)
- Put in strategies to allow for more open communication so fears can be expressed and acknowledged.

#### Possible alternative scenario

- Mood deteriorates
- At the last minute she refuses the placement and it is in danger of breaking down
- Social worker assess and calls multidisciplinary meeting to discuss the situation

#### C Type hours unit cost total cost 1.5 40 60 Tm interview gP appointement 0.25 199 49.75 support to atend Gp 3 20 60 liase with family 2 40 80 169.75

#### Cost

GP referral	0.25	199	49.75
prescription	1	41.35	41.35
support to attend appointment	3	20	60
social work visit report and liaisng	3	40	120
multi agncy emergency meeting	2	687	1374
			1645.1



## **Cost Benefit Analysis**

**Keeping Safe** 

**Example 6** 

Unless mentioned the data source used is the Personal Social Services Research 2015/16

# Keeping Safe



A man with cerebal palsy . He has mild learning disability , good understanding but limited verbal communication . He is familiar with using Talking Mats as a way to communicate his views. He lives in a small group home.

His community learning disability nurse was reviewing his views on well-being.

#### What happened

A Well being Mat' was carried out in which he expressed :



- difficulties talking about himself -talking mat helps him
- eating wasn't going too well, worried about choking and that means he does not choose a varied diet
- not liking the dentist
- exercise wasn't going well would like to try using the new parallel bars in the centre to help improve his strength.
- managing money and making decisions were not going as well for him.
- Worries about the safety of his belongings.

This information was discussed at his next review meeting. Steps were put in place re increased re supporting his autonomy and safety of his belongings and parallel bars tried at sport centre A referral to Speech and Language Therapy was made around his eating concerns

#### Cost

Tm interview	1	44	44
Planned Review meeting	1	264	264
referral to SLT	3	44	132
guidelines dissemenated re eating and drinking	1	44	44
laison with key worker re eating and autonomy	3	24	72
further work on automony and safety		44	132
			688

#### Possible alternative scenario

- His concern about eating and drinking were not picked up
- There was a choking incident ( risks of deterioration of eating and drinking are associated with aging and cerebal palsy)
- His mood deteriorated
- Referall to doctor and speech and language therapist
- Further investigation such as video-fluoroscopy
- Adapted diet and input to educate staff and client re future eating and drinking support



#### Cost

Non intervention - choking incident and dysphagia			0
GP referral	0.25	199	49.8
referral to SLT	3	44	132
investigation at the hospital e.g. videofluroscop	1	580	580
training for staff on dsyphagia	3	44	132
staff	8	33	264
Emergency Review meeting	1	395	395
further work to explore poor mood	3	44	132
			1685







#### Summary of the cost benefit intervention

Case	Talking Mats intervention	alternative scenario	saving	Percentage saving
1	88	161	73	45
2	704	21534	20830	97%
3	139800	234342	94542	40%
4	385	1575	1190	75
5	170	1645	1475	89
6	688	1684	996	59
TOTAL	141747	260780.75	119033	
	average		19,851	67%

The financial return to organisations investing in Keeping Safe Talking Mats training were based on 12 people attending the training and then averaged out for 1 person using the resource 6 times.

#### Discussion of cost benefit

There is a significant financial advantage to services using Talking Mats. For each pound invested in the Keeping Safe training there is a potential saving to public services of £23.00. This however needs to be understood in the context of services that are joined up because the preventative work may be a cost to one service e.g. case 1 advocacy but the saving in that example is in the health service.

In learning disability services it is easy for costs to accelerate quickly particularly if an emergency placement is required. The potential for this is clearly demonstrated in case 2 if services don't respond effectively challenging behaviours can escalate and relationships and placement are at increased risk of breakdown. Talking Mats can help provide staff with a comprehensive and accessible framework to help them really listen to people who can find it difficult to articulate what is really going on for them e.g. issues of pain, relationships or levels of support. It provides a way to then turn those views into actions that can be monitored and reviewed. It is these early interventions that can save money but also improve quality of life.

Six cases were analysed across a broad spectrum of services. Further cost benefit analysis using either :

- More cases
- or cases focused on what particular type of service

may well result in different figures but the trend shows that listening to service users is not only good practice but clearly saves money







#### **Sustainability**

We have created a specialist Talking Mats resource that will allow practitioners trained in the Talking Mats framework to implement Keeping Safe.

This has had a soft launch in London March 17th and a marketing plan to extend the use of the resource is being drawn up. This will include exploration of webinars to enhance the learning experience.

The marketing plan will aim to encourage its use

- 1. With people with a range of communication disability not just learning disability. It has been positively trailed with a man with an acquired neurological and young people with mental health conditions.
- 2. Outwith Scotland

#### Within Scotland

The 22 Keeping Safe accredited trainers are continuing to train people who work in the field of learning disability to use the resource. All trainers have received an allocation of resources and training is ongoing. Once the funded resources are finished, (190 sets remaining, anticipated July 2017) the trainers will be encouraged to maintain training and links with Talking Mats. From 2018 they will require to pay an annual licence fee of £75.00 and a participant's fee which includes the resource. This is currently £30.00 per person. This is a substantially reduced price the normal price is £55.







#### **Dissemination**

- A paper was published in March 2017 in the Tizard Learning disability review which focuses on the factors to consider when designing an accessible resource.<sup>3</sup>
- Led a workshop at the Gender based violence conference led by NHS health Scotland. This conference recognised the risk for women with mild learning disability in particular of being at risk from violence
- Wrote a blog for Safe Lives Ending Domestic Abuse
   <a href="http://www.safelives.org.uk/practice\_blog/helping-women-learning-disabilities-express-their-views">http://www.safelives.org.uk/practice\_blog/helping-women-learning-disabilities-express-their-views</a>

The Keeping Safe resource is being presented at

- The Scottish Speech and Language Therapy Learning Disability Clinical Excellence Network in April 2017
- the AGOSCI conference, Melbourne, Australia in May 2017
- Prevention of Abuse Seminar organised by Scope Victoria Australia

An abstract application to hold a workshop has been submitted to the Royal College of Speech and Language therapists annual conference to held in Glasgow in September 2017-The Keeping Safe Project

The Talking Mats web-site hosts blogs about the use of the Keeping Safe resource. These are disseminated via active Social Media.

Learning Disability Review, Vol. 22 Issue: 2, pp.57-65, doi: 10.1108/TLDR-10-2016-0028

<sup>&</sup>lt;sup>3</sup>Lois Cameron, Rhona Matthews, (2017) More than pictures: developing an accessible resource", Tizard





#### Recommendations

Throughout the project we have been seeking feedback from practitioners . These recommendations come from what they tell us about the use of the resource in services through our Scotland, their stories have been invaluable. We have divided the recommendation into those that focus on the

- Resource and Training
- The themes that emerged from the views of people with learning disability as they used the resource and reflected on their lives
- The application of a cost benefit analysis

#### The Keeping Safe resource and training

- 4 Health board areas in Scotland do not have Keeping Safe trainers- NHS Highland, NHS Western Isles, NHS Orkney and NHS Shetland. It was a target of the project to have trainers in the 14 health board areas and we are keen to have trainers in those authorities.
- Investigation The Keeping Safe resource is a tool to support raising of concerns.
   Staff commented that having a set resource supported them to remain neutral and avoid making assumptions. If a person does raise a concern then that organisation's ASP framework applies in the same way as if a concern is raised verbally. As yet Talking Mats do not have a resource to support the investigation of an issue and the ability to create this in conjunction with police or justice departments would support investigative practise with people with communication difficulties.
- Gender based violence The risks for woman with mild learning disabilities who are living in the mainstream with minimal support is huge and this risk was recognised at the NHS health Scotland event in Oct 2016. Often communication supports are not used with people who are verbal but people are silenced for many reasons. We know that Talking Mats is a helpful support to enable people who are verbal to communicate more effectively and at a deeper level therefore a project that focused on this group in more depth may be provide support to help woman disclose.
- Talking Mats and people with autism. We know that a lot of people with autism value Talking Mats as a thinking tool and we also know that for some people with autism they use it in a different way. It would be beneficial for these people and for the staff who support them if we could explore adaptations to the framework to enable it to be more accessible to a wider range of people.

#### Themes that emerged

• **Transition** - People already vulnerable become increasingly so at times of change, either of placement or staff. One story described how regular use of the Keeping Safe Thoughts and Feelings topic helped to reduce a man's anxiety in the build up to





a placement change. Transition as topic in itself would also benefit staff, allowing them to 'check in' with people as change is approaching. Certain specific options would be included, e.g 'staff change', 'finding way around' so a new Talking Mats resource would be necessary.

- Keeping In Touch- ~Sustaining friendships and moving a relationship on to a more
  intimate level were raised as concerns in the Talking Mats. For people with learning
  disabilities their social networks are far more limited. 13 out of 37 people who
  completed the Thoughts and Feelings Mat admitted to feeling lonely. One person
  admitted to keeping this a secret from her family, as she did not want to worry them.
- Internet Safety- Social media was used 9 times out of 28 interviews. 8 people reported it was going well and 1 it was not. Only had two stories which expanded on this topic showing the different impacts it can have on relationships. For one it was a positive relationship, for another it was abusive and had a significant impact on this person's wellbeing. 'Increasingly, children and young people are learning and socialising using online resources'4. Talking Mats would be an effective tool to check in with people how their use of Social Media was going.

#### **Cost benefit Analysis**

Cost benefit analysis The Keeping Safe Talking Mats resource has been shown to
be effective in terms of saving services money therefore should have a much higher
profile in terms of learning disability planning, contracts and service monitoring.
Person centred care is cheaper but there is still a tendency to think it will cost
services time and effort when the reverse is true and there needs to be a culture shift
that allows services to be more flexible and plan around the individual recognising
that it is in both their and the services benefit to do so.

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<sup>4</sup> https://www.mencap.org.uk/sites/default/files/2016-11/Internet-Safety-web-2016.pdf



#### Appendix 1



## **Keeping Safe**

## A Talking Mats resource to support people reflect on how their lives are going and express concerns



The Scottish Government Keys to Life strategy commissioned Talking Mats Limited to develop a resource which could be used across Scotland to enable people with learning disability raise concerns. This recognises the fact that people with learning disability are at risk of inequality in terms of their health and life opportunities, and vulnerable to increased risk of abuse.

The Keeping Safe project has resulted in a resource that allows people with learning and communication difficulties to raise concerns—both big and small. It creates a listening space and supports staff to open up conversations in a way that is non-leading. The framework incorporates topics that are sensitive and sometimes difficult to discuss offering a degree of safeguarding.

#### What's in it? There are 3 topics







Your well being

Relationships Thoughts and Feelings

#### Summary of project

The project has trained over 550 people in Scotland to use the resource with people with learning disabilities. Trial and feedback from its use allowed the resource to be added to and adapted, and stories of its use highlighted the issues for people and the person-centred actions that resulted.

There are 22 trainers across Scotland continuing to run courses.

An earlier report (available form www.talkingmats.com) details the background and methods used in the project.

The resource was successfully trialled with young people with mental health problems and people with acquired brain injury. The is now available to purchase

#### Feedback from use of the Keeping Safe resource



rather than just agree with us

Example of a Thoughts and Feelings Met



"From this mat we found out she was womied"

Example of a Relationships mat



'Wants to most his girlfriend out with the day centre, but doesn't know how to organise this'



He recognised that lots of things were going well in his life but that he wasn't handling stress

#### People with learning disabilities found the Keeping Safe resource a helpful way to:

- o discuss new information (89%),
- o discuss and resolve fears (84%)
- o Support thinking (89%)

Staff stated specifically it is an effective way to gain new information and support discussion of sensitive topics (66%)

#### Benefits for Organisations:

A cost benefit analysis showed that using the Keeping Safe resource can save organisations money by supporting people to raise concerns at an early stage and prevent issues escalating



www.talkingmats.com



Funded by the Scottish Government