Appendix 14- List to be Completed by Teams of Those who have Given Consent to be Contacted

List of Clients
Consent Obtained for Bronwen to Contact
Re: Research into Emotional Recognition and Regulation- Version 2 20/7/2012

Staff Name_______________________

Client Name	Contact Number	Spoken to - date	Consent Obtained
Following consent being obtained a brief note to this effect will need to be made in the Service users case notes.			

Appendix 15- Recruitment Poster Providing Teams with Information that can be given to Potential Participants

Will you take part in some research?

Research projects help us find out what people with learning disabilities think and feel and do in different situations

My name is Bronwen Davies

I am asking people to answer some questions about their feelings, like sad, happy, worried. All your answers will be private and between me and you.

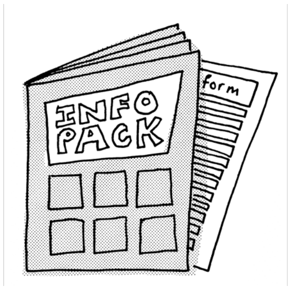
It will take about ½ an hour and I can meet you anywhere you want

I would also like to ask someone who knows you well about your feelings and behaviours. You can chose who that is but they need to agree too. It will take ½ an hour with them too!!!

If you will meet with me I will tell you more about the research and you can choose whether you want to take part.

Thank you

Appendix 16- Service User Information Sheet



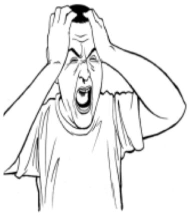
Service User Information Sheet

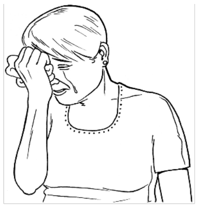
VERSION 4- 21/09/2012

- My name is Bronwen Davies
  I am training to be a Clinical Psychologist
- I would like to invite you to take part in a research project I am doing

- Research projects help us find out what people with learning disabilities think and feel and do in different situations.
- This leaflet will tell you about the research project

Why have I been asked to take part?





- I am asking people to answer some questions about their feelings, like happy, sad, worried.
- This will take about ½ an hour

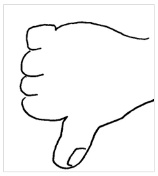
Who else will take part?

- I would like to talk to a carer who knows you well, for example a family member or staff member.

- I would like to ask your carer to fill in questionnaires about your emotions and behaviours.

- I want to see if your understanding of your feelings is the same as your carer's views of your feelings and behaviours.

Do I have to take part?



- It is your choice to take part

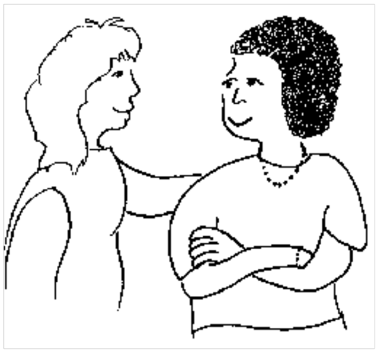
- If you do not want to complete the questionnaires with me that is ok

- Taking part will not affect your care and treatment by learning disability services.

- If you agree to meet with me but change your mind that is ok. You can change your mind at any time

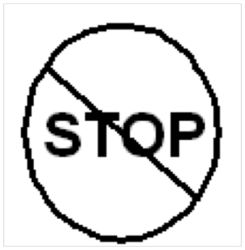
Will taking part in the project help me?

- Taking part will not make a difference to your care and treatment but I hope it will help other people.
- I hope the project will tell us about the feelings of people with a learning disability and how these impact on challenging behaviours.



- This may enable staff and carers to recognise the feelings of people with learning disabilities and provide better support around these.
- I hope you will enjoy taking part.

Might any of the questions upset me?



- As the questions are about your feelings they may remind you of situations that have made you feel like that.

- We can stop completing the questionnaire at any time if you want to or you feel upset
- If you are very upset I can arrange for you to speak to someone else

Will anyone else be told what I have said?

- Everything you tell me is Confidential (Private), nothing will have your name on it.
- This means I will not tell anyone else what you have said to me.
- I will only break this rule if you tell me something that makes me worried about the safety of you, or someone else.
- If I am worried, I will talk to a member of the community team who knows you, so we can keep you safe. I will let you know if I have to do this.

What will happen if I want to take part?

- If you would like to meet with me a member of staff will help you fill in a consent form.

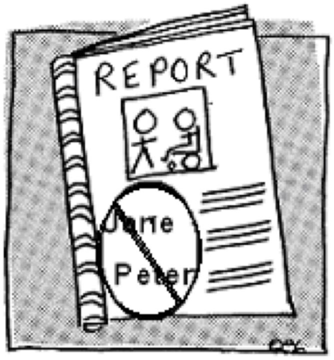
- You can choose where you would like to meet. We could meet at your house, the day centre or at the Community Team office.

- I will arrange a time to meet you

- If you would like someone with you while we complete the questionnaires that will be ok

- I will contact the family or staff member you choose and meet with them to complete the other questionnaires or post them to them.

What happens when the research ends?



- When I have spoken to 55 or more people I will write a report about what everyone says.

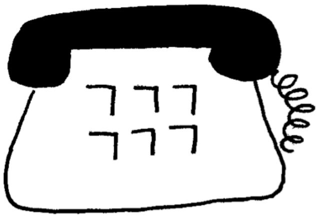
- I will not put any names in the report

- If you would like to know about the findings of the project I can send you a report.

What if there is a problem?

- If you are unhappy with this project you can talk to your Manager or a member of staff who will help you make a complaint.

- The project is insured by Cardiff and Vale University Health Board if you need to make a claim.

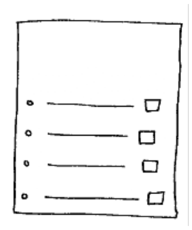


What if I have more questions?

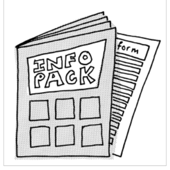
- You can contact me on 07703 324922 or my supervisor, Dr Rosemary Jenkins (Consultant Clinical Psychologist) on 029 20 870 582.

Appendix 17- Service User Consent Form

VERSION 4 28/09/2012



Service User Consent Form



	Yes	No
Have you read (or had read to you) the information sheet (version 4- 21/09/2012)?	[ ]	[ ]
Do you understand what you have been told about the project?	[ ]	[ ]
Have you asked all the questions you want?	[ ]	[ ]
Do you understand that you can stop taking part at any time?	[ ]	[ ]
Do you understand that everything you say will be confidential unless Bronwen is worried about someone's safety?	[ ]	[ ]
Do you agree to the things you say being written up in a report?	[ ]	[ ]
Do you agree to Bronwen contacting you to arrange a time and date to meet?	[ ]	[ ]

	Yes 👍	No 👎
Do you agree for Bronwen to contact a member of your family or staff that know you well. They will be asked to complete questionnaires about your emotions and behaviours.	[ ]	[ ]
If yes, who?____________________________		
Do you agree to the things _______________ says being written up in a report?	[ ]	[ ]

If you do not want to take part, do not sign your name.

I agree to the above:

________________________ ____________________ ___________

Service User's name (printed) Signature Date

Contact Number____________________

I, the undersigned, confirm that I read through and discussed the information sheet with the participant who has agreed to take part in the study:

________________________ ____________________ ___________

Name of person taking consent (Printed) Signature Date

Appendix 18- Carer Information Sheet

VERSION 4 28/09/2012

STAFF / CARER PARTICIPANT INFORMATION SHEET

An Examination of the Emotional Recognition and Regulation Skills of Clients with a Learning Disability.

I would like to invite you to take part in a research study which is being carried out by myself, Bronwen Davies (Trainee Clinical Psychologist), under the supervision of Professor Neil Frude, Dr Rosemary Jenkins (Consultant Clinical Psychologists, Clinical Psychology Training Course), Dr Caley Hill and Dr Cathy Harding (Clinical Psychologists, Learning Disability Services, Aneurin Bevan Health Board).

Why have I been invited to take part?

You have been identified by ____________________________ as someone who knows them well. They have agreed to take part in this research and have given me permission to contact you and ask you to complete questionnaires around their behaviour and emotions.

You have been invited to take part because you are a family member, a member of staff or paid carer, who has been involved in supporting ______________________ for at least one year.

Before you decide whether to take part it is important for you to understand why the research is being done, and what it would involve for you. Please take time to read the following information carefully. If you want to ask any questions or would like further information then please free to contact me via the address, email or telephone number below.

What is the purpose of this study?

Some people have difficulty recognising and regulating their emotions. We are interested in whether people with learning disabilities have emotional recognition and regulation skills and whether this relates to their behaviour. It is hoped this study will promote the understanding of people with learning disabilities emotional needs.

Do I have to take part?

No, this research study is voluntary so it is up to you if you want to take part or not. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form.

If you decide to take part and then change your mind later, you will be free to withdraw from the study at any time. You will not have to give any explanation and any information you have given will not be used in the research.

What am I being asked to do?

This information sheet and a consent form will be provided and if you are happy to take part the signed consent form needs to be returned to the researcher. The researcher will contact you to explain about the study and to answer any questions you may have. Agreement will be made about whether to arrange a time to meet with you to ask you to complete two questionnaires or they can be posted out to you. When you have completed the questionnaires about ____________________________ emotions and behaviours they need to be returned to the researcher.

The questionnaires can be completed at a time and place that is convenient for you and will take approximately 30- 45 minutes. The questionnaires will not have your name on them and therefore will be anonymous and confidential.

What are the possible advantages of taking part?

There are no direct advantages to taking part. It is hoped that participants will welcome the opportunity to contribute to a better understanding of service users' emotions and their relationship to behaviour. We hope this will inform future interventions and service delivery.

What are the possible disadvantages of taking part?

There are no known risks involved in taking part in this study, however, some participants could find the topic sensitive and issues may arise which cause upset. If this occurred you could stop immediately, you would be under no obligation to continue and could withdraw from the study altogether.

Will my taking part in this study be confidential?

Yes. The researcher follows a strict ethical and professional code of conduct that requires all information obtained remains confidential and anonymous. You will not be able to be identified by anyone other than the researcher. Each of the questionnaires will be given a number to connect it with the other questionnaires completed about the service user, they will contain no personal data and they will be stored safely. Only the researcher and supervisors will have access to the questionnaire data.

This confidentiality would only be broken if I became aware of malpractice, misconduct or possible risk to you or another person. If this occurs, I will discuss this information with the Community Team Manager, or Lead Manager, in accordance with NHS procedures and my professional codes of practice. I will let you know that I am going to do this.

What will happen to the findings of the study?

The results of the study will be written up as a doctoral thesis and submitted as part of my examinations towards a Doctorate in Clinical Psychology. Upon completion of the study a summary sheet outlining the main findings will be sent to those participants who have indicated that they would like a copy of the research outcome. It is hoped that the findings from this study will be presented in an academic publication, local service meetings and/or at national conferences.

What if I have a problem with the study?

If you are unhappy with any aspect of this study or have any concerns, please contact the researcher or alternatively Dr Rosemary Jenkins (contact details below). If you remain unhappy and wish to complain formally we will give you contact details of other people who may be able to respond to your concerns. The researcher is insured for this undertaking this project via Cardiff and Vale University Health Board.

Who has reviewed this study?

All research carried out by the NHS is reviewed by an independent panel called the Research Ethics Committee. This is to ensure the safety, rights and welfare of anyone who participates in a research project. This study has been reviewed and given favourable opinion by the South West Wales Research Ethics Committee.

Further information

If you have any further questions about taking part in the study or require any more information please do not hesitate to contact me (Bronwen Davies) at the Psychology Department on 02920 870582, email me Bronwen.Davies3@wales.nhs.uk or contact me at the address above, and I will get back to you as soon as possible.

THANK YOU FOR CONSIDERING TAKING PART AND TAKING THE TIME TO READ THIS INFORMATION SHEET

Appendix 19- Carer Consent Form

STAFF / CARER CONSENT FORM

Study Title: An Examination of the Emotional Recognition and Regulation Skills of Clients with a Learning Disability.

If you decide to take part in this study, all of the information you provide will be kept confidential. You are under no obligation to participate and have the right to withdraw at any time.

Name of researcher: Bronwen Davies

	Please initial the boxes if you agree
1. I confirm that I have read and understood the information sheet version 4 28/09/2012 for the above study. I have been given the opportunity to consider the information and have had any questions answered adequately.	[ ]
2. I understand that my participation is entirely voluntary. I will be free to withdraw at any point, without giving any explanation, and any data I have given up to that point will not be used for analysis.	[ ]
3. I understand how my confidentiality will be ensured.	[ ]
4. I agree to complete two questionnaires, about behaviour and emotions, and to this data being included in a report to be submitted by the researcher as part of her doctoral qualification.	[ ]
5. I agree to take part in the above study.	[ ]
6. I would like a summary of the research findings on completion of the study.	**Please circle YES NO**
If you have indicated 'yes' to the above question please provide details of where you would like the summary sent (i.e. email or address):	

_____________________________ _______________________ ________________

Participant's name (printed) Signature Date

_________________________________ _______________________ _____________

Name of person taking consent Signature Date

Appendix 20- Demographic information Sheet

Demographic sheet

Number _____

Client Gender:

Client age:

Carer Relationship:

Time known to the client:

Appendix 21- Instructions Sent to Carer Participants when Questionnaires where E-mailed or Posted to Them.

Dear ____

I have enclosed an information sheet for you that tells you about the project. I have also enclosed a consent form. I would be grateful if you could tick or initial all the boxes and sign and date the participant line if you are happy to proceed. There are 2 questionnaires.

With the challenging behaviour checklist the three keys for frequency, management difficulty and severity are on the inside front page. There are 3 columns on page 3 and 4, the first column is frequency (F), the second is management difficulty (MD) and the 3rd one is for severity (S). On pages 5 and 6 there are only 2 columns, the first one F for frequency and the second MD for management difficulty. Please complete the F column box for every behaviour listed. If you put a 0 in the F box you do not have to complete the other 2 boxes. If you put any other number in the F box, please also place a number in the boxes for MD (management difficulty) and S (severity). The key for F, MD and S are all on the front inside page. There are also questions at the end of each section and on the back page, I would be really grateful if you could complete these also.

The observer alexithymia scale has a key at the top of the page- 0= never, 1= sometimes etc. Please circle a number in response to each question.

You don't need to put “service user’s” name or any other identifiable info on the questionnaires, just send them back to me and let me know they are from you and I will pair them up.

I am finishing data collection on 30th January so I would be grateful if you could get them back to me as soon as possible, prior to this.

I would like to take this opportunity to thank you for your time and support in completing my research and if you would like I can send you a copy of the outcomes when it is complete.

Many thanks again

Bronwen

Appendix 22- A table showing the distribution of all of the variables

Skewness	**Kurtosis**	**Normal**
Challenging Behaviour Management Difficulty	Challenging Behaviour management difficulty	Worried Total
Challenging Behaviour Frequency	Challenging Behaviour Frequency	Angry Total
Aggression severity	Aggression Severity	Emotional Recognition Questionnaire total
Happy Total	Happy Total	Alexithymia Questionnaire for Children Difficulty Describing Feelings
Sad Total	Scared Total	Alexithymia Questionnaire for Children Difficulty Identifying Feelings
Cognitive Emotional Regulation Questionnaire Self-Blame	Cognitive Emotional Regulation Questionnaire Other Blame	Alexithymia Questionnaire for Children Externally Oriented Thinking
Cognitive Emotional Regulation Questionnaire Catastrophising	Time known to client	Alexithymia Questionnaire for Children Total
Time known to client		Cognitive Emotional Regulation Questionnaire Acceptance
Observer Alexithymia Scale Somatising		Cognitive Emotional Regulation Questionnaire Positive Refocusing
Observer Alexithymia Scale Rigid		Cognitive Emotional Regulation Questionnaire Refocus on Planning
		Cognitive Emotional Regulation Questionnaire Positive Strategies
		Cognitive Emotional Regulation Questionnaire Negative Strategies

		Observer Alexithymia Scale Distant
		Observer Alexithymia Scale Uninsightful
		Observer Alexithymia Scale Humourless
		Observer Alexithymia Scale Total