



Hywel Dda NHS Trust – CLDT



## Relationships



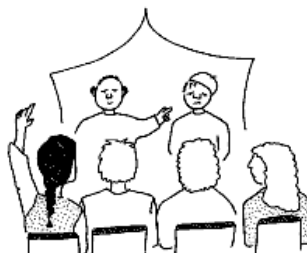
We all need relationships...

**But what are the Barriers? Do we have the Solutions?**



**A report of the Conference held in Ceredigion on 10<sup>th</sup> June 2009 hosted by The All Wales Forum of Parents and Carers of People with Learning Disabilities.**

**Designed and led by local professionals, parents and carers, and people with learning disabilities to share views and ideas.**



This report is written to capture the ideas and views expressed by the participants in the conference entitled **Relationships** held in Ceredigion on 10<sup>th</sup> June 2009.

## **Background**

The idea for the conference arose from discussions that had been taking place in the **Ceredigion Learning Disability Service Implementation and Review Group**.

This group is convened by Ceredigion County Council to discuss the issues and challenges involved in providing the best service to people with learning disabilities in the county.

Members of the group are: - The Senior Manager for Learning Disabilities; the Team Manager Community Team for Learning Disabilities; Two people with learning disabilities; a parent and carer representative from Ceredigion Parents and Carers Forum; a voluntary sector representative – Mencap Cymru; the Regional Development Officer for the All Wales Forum for Parents and Carers; the Manager of Ceredigion People First; a Senior Manager from the Ceredigion Local Health Board and the Day Services Development Manager Ceredigion Social Services.

The Senior Manager for Learning Disabilities co chairs the meeting with a person with learning disabilities with support from Ceredigion People First.

One topic that appears repeatedly on the agenda is the difficulty for people with learning disabilities to form meaningful relationships, either sexual or platonic. Clear policy and procedure guidelines, for everyone concerned, were identified as a major requirement. The group agreed that it would be valuable to have a one day conference where constructive, wide ranging discussion could be encouraged to assemble a picture of the current situation. The contributions on the day could be gathered and used to support the development of a

policy which meets the needs of people with learning disabilities in Ceredigion.

The All Wales Forum agreed to host a conference on the topic in the county.

A small group facilitated by Gavin Wood, Manager for the Ceredigion Community Learning Disabilities Team, began to meet to organise a conference day with the title '**Relationships**' to take place on 10<sup>th</sup> June 2009 at Ty Glyn Hotel, Ciliau Aeron, Ceredigion.

A Community Learning Disabilities Nurse joined the group along with the Manager for Ceredigion KeyRing- Living support Networks.

It was decided that the **aim and objectives** for the day would be:

### **Aim**

**To promote a discussion around the barriers that people with a learning disability face in trying to form and maintain relationships.**

### **Objectives**

To:-

- 1. Involve people with learning disabilities, staff, including managers, parents and carers.**
- 2. Produce something concrete from the day, such as a report; a joint statement or joint working on a policy.**
- 3. Raise as many issues as possible, while creating a coherent programme for the day.**
- 4. Share all the different points of view.**
- 5. Make sure that the voice of the least able is heard on the day.**

We decided that:

- The conference would be planned to be a contribution to the discussion around relationships for people with learning disabilities. We would not be able to give conclusive solutions but would facilitate an open and sensitive discussion.
- It was important to engage with the different perspectives held which had an effect on relationships. We wanted to create a day in which people felt that it was safe to contribute honestly. We decided that the closed workshop model for discussion was the most appropriate to facilitate this.
- To design the programme so that the morning would be used to illustrate the challenges and that the afternoon would illustrate the possible solutions or ways forward.
- The group was concerned that the voice of the least able was heard on the day. We agreed that one of the most effective ways of conveying ideas is through the use of drama. We were fortunate to have the resources within the group. Ceredigion People First were able to offer to create dramatic representations of the challenges and the possible ways forward.

### **The Conference Day**

The conference was well attended with sixty eight participants. The largest group of participants were people with learning disabilities. The next largest group were support workers. The third largest were managers and the smallest group were parents and carers.

## **The Co-Chairs.**

The conference day was co-chaired by **Jonathan Richards**, who is a person with learning difficulties and Chairperson of Ceredigion People First, and **Pauline Heyes**, the manager of Ceredigion KeyRing – Living Support Networks.

Jonathan Richards welcomed everyone and introduced the first part of the programme, a short piece of drama created and performed by Ceredigion People First. The idea behind the scenario was to illustrate the frustrations and challenges experienced by people, who rely on support in their everyday lives, trying to form a relationship.

The audience responded very favourably to the drama which discussed the issues using a little pathos and a lot of comedy.

## **The Workshops**

Following the drama, the conference participants dispersed into one of four workshops devoted to their own personal constituency/ role, ie, for people with learning disabilities; parents and carers; support staff and managers. This was to create a safe atmosphere where people were able to candidly discuss their perspective amongst their peers.

The discussion in the workshops was held in confidence. The questions to be considered from each perspective were: -

Morning workshop:

**‘What are the barriers to being able to form relationships for people with a learning difficulty/disability?’**

Afternoon workshop:

**‘What are the possible solutions or ways forward?’**

The views and ideas emerging from the workshops form the central essence of this report. The main messages that emerged are contained in the summary.

**The Conference Speakers**

**Pauline Young**, Chairperson of the All Wales Forum was the first of two speakers.

Pauline is the mother of an adult son with Down’s syndrome; the Wales representative of the Family Fund UK Board and is also a member of a number of LD associated organisations including the LDIAG. In her presentation Pauline discussed the disparity in sexual education and the lack of guidance in sexual matters for people with learning disabilities. She discussed the way forward through a person centred approach. The presentation was delivered in a positive, matter of fact way which the audience evidently appreciated when measured by the applause and discussion that it generated.

**Andrew Kennard**, Partner of Donna Martindale and father to baby Chelsea was the second speaker.

Both Andrew and Donna have learning difficulties. Andrew described the challenges that he and his partner have faced in becoming a family unit. He described the obstacles that were in his path and how he and his partner Donna are dealing with them. He was able to tell the audience of the happiness and satisfaction that having a family had given him and his partner. He offered his experience as a positive role model.

A lively question and answer session followed. Many positive comments were written about this presentation on the evaluation sheets from the day.

Following this was the second drama depiction from Ceredigion People First. This was a scenario to represent a possible positive solution.

## **What we heard in the workshops**

The following pages are written by the workshop leaders using the information from the discussions captured on the flip charts.

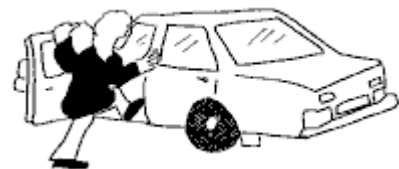
### **The Perspective of People with with learning disabilities.**



#### **Barriers- what stops you from having healthy relationships**

These are some of the comments people made;

Transport is a problem. How to meet people when you might live too far away? How to get out in the evening?



Many people have had no information or have never had any sex education ever.



Not enough support staff

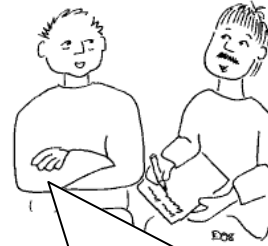
Feeling love and not wanting to say you love someone

Unprotected sex

Saying no when you want to.

Being pushed around and forced to have sex

A lack of privacy and  
A lack of own space



IT'S NOT JUST SEX

Some people think that people with learning difficulties should not have relationships or sex



## Transport

People have to rely on parents, friends or support workers in rural areas to be able to get out and meet others.

Support workers shifts often do not coincide with when people want to go out.

There may not be enough staff in supported housing, so that people can make separate choices about what they want to do.

Some people's parents are elderly and if it weren't for Gateway organising a bus they would not go out.

One person who has support with community connections which was family aide would prefer a male worker to go out with them.

## **Expectations and opportunities**

Many people have low expectations of what they would be allowed to do and what support they could get from their families and workers. They would not for example invite a partner round to their home. The consequence is that they may never have had any opportunities for privacy and intimacy with their partners.

Many people have had little or no information about: relationships, being safe and making the rights choices for themselves or their rights concerning sex and relationships.

Some people expressed loneliness and isolation, being without a relationship for many years, not being asked out or going places where they could meet people.

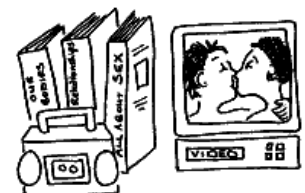
## **Being safe and making good choices for yourself**

Four women from the group had experienced invasive behaviour and violence from partners. Two were forced to have sex and one to have sex without protection. They had to go through police investigations, taking DNA swabs and interviews with social workers.

Some people could not make good choices especially around sex because they had misinformation or come to the wrong conclusions about what was safe and what wasn't.

Very few people had any information about homosexuality, some people held prejudiced views about this or it was a source of embarrassment.

## **Ideas, Possible Solutions**



Some of the things expressed in this part of the day were a combination of advice, discussion topics and what people wanted.

### **What I want**

Get a boyfriend and give him a kiss

Cuddling – showing love and being loving

Going out for a drink and going to the disco

Getting married

People with learning difficulties could provide some of the training or the support groups for men and women.

### **It's important to:**

Love yourself and appreciate who you are. You're more likely to enjoy your life and also get into a relationship.

Be happy, don't get embarrassed about it

Be friends with your boy friend

Look at your body

### **Rights**

We can have sex we are all adults

Consensual sex is where both people agree to have sex to be in a relationship.

### **Transport**

There seemed no easy answers to this, but obvious ones were:

More transport and more buses, ask your key worker for help.

Travel on your own, in a taxi, with an escort

Get travel training.

### **Person Centred Planning**

This is where you think about what you want in your life and you write it down.

Support workers and people in your circle of support are meant to help you get what you want.

You might need more money for transport to go out and meet people. Direct payments: to enable you to have more support to do what you want.



### **Relationships with people of the same sex**

If you want to experiment – go to a meeting, where you can meet other gay, lesbian or bisexual people. There are probably support groups locally.

### **Solution to parents who don't like your partner**

You could get rid of your partner,

Not see your family

Talk to the parents

Get an advocate like Jan Kench to help you to stand up for your rights.

Or you could change society and stand up for your rights.

### **Our image**

There could be more films about people with learning difficulties – with real people who have disabilities.

Society should scrap images that depict people with disabilities in the wrong way.



## **If things are seriously not right in your relationship**

You can talk to the:

Police – if it's violent; Housing manager; Social services;

Health/NHS clinic

And take things to court if people are breaking the law.

## **Parenting**

I want someone to help me with my daughter

I want to get our daughter back

Having more support to look after your baby

Have a chance to be a family

Go on parenting courses



## **If relationships are not working**

Divorce if it's not working

Trying out a different partner

Sometimes I feel vulnerable and gullible.



## **Ideas to meet people are:**

Speed dating clubs

Going out, going to groups

We need more Information and more support.



## **The Support Workers' Perspective**

This group was made up of a variety of front line staff, such as day care workers; domiciliary staff; community nurses; community learning disability team staff and voluntary sector staff such as advocacy workers. Because of the diversity of roles and size of the group it was necessary to split the group into two. There was a lively and engaged debate in both groups with the following points being put forward:

### **The Barriers**

#### **Practical** barriers:

- Lack of transport
- Poor access to public transport services.
- Lack of money
- Communication difficulties
- Lack of opportunities to socialise
- Lack of support staff
- Lack of privacy
- Lack of education/support for parents/support worker.
- Ignorance about sex
- Not enough support to be able to maintain relationships

#### **Attitudinal** barriers:

- Fears around 'informed consent'.
- Fears/anxiety around the idea or reality of people with learning disabilities/difficulties having sexual relationships
- Staff training only concentrating on manual handling; food hygiene and not enough emphasis on emotional/relationship
- Anxiety about possible conflict between support staff and parents.
- Expectations of some parents and carers that people with learning disabilities should not have relationships/sex.
- Lack of knowledge about sex
- Lack of training

- The complexity of meeting the expectations of the different perspectives involved ie the people themselves; their parents and carers and support staff.
- The attitudes of broader society.
- Trying to meet the needs of individual expectations
- Pressure of work
- Responsibility for people's emotional well being without having been properly trained.
- Difficulty of making friendships in the community
- Schools not providing good relationship training.
- Poor knowledge of where to signpost when needs arise

## **Solutions**

### **Practical:**

- Training to all parties: People with LD; Parents and carers; Support staff.
- Make this training a condition of staff contracts
- Regular, updated relationships education
- Good communication fostered between all parties
- Ask people with LD what they want
- Consider capacity and consent from the point of view of encouraging relationships rather than hindering them.
- Support for people to have relationships regardless of disability including profound disabilities.
- Lobby AM's decision makers and others in the broader community for support.
- Put values into practice
- Need to retain support staff in their posts to provide consistency
- Support staff need back up from their managers. They need guidance and support from care providers/ managers to be able to make the right decisions on the spot.
- Consider the support needs of all parties ie peer support;
- Emotional support for parents; people with LD and support workers.
- Access to dating agency in Ceredigion – people with LD to have access to professional advice
- Information should not be lost in changeover of staff

## **Attitudinal:**

- Staff trained to recognise their own feelings and talking through emotional issues.
- Staff trained to be able to listen to the feelings of people with learning disabilities and offer real support.
- Support staff knowing where to go for information and help e.g. Family planning
- It is everyone's responsibility to combat prejudice and outdated ideas.
- Information on emotional issues should be more accessible.
- More efforts should be made to integrate into the broader community.

The consensus of views in the workshop was:

That support staff acknowledge their important role in supporting people with LD to form and build relationships.

That people with learning disabilities have the right to expect support; help and acceptance of relationships sexual or otherwise. In order to achieve this staff need approved training and management support especially around complex issues.

Participants stated that it should be an expectation that people will develop a variety of relationships. That it should be considered that anything otherwise would be considered a problem and dealt with as an important concern.

## **The Parents and Carers' Perspective.**

Parents and carers formed the smallest group by far at the conference. It was felt that perhaps this was to be expected given that many would have had to take time off work to attend a daytime meeting on a weekday.

But in our discussions it emerged that there were other reasons for poor attendance. One was that the topic of forming relationships of a loving or sexual nature is not really an issue for some parents and carers. This is because they feel that the nature of their child's disability makes it hard for him or her to relate to their peers. Other parents may have stayed away because their worries in this area are so great that they find discussing it very upsetting. One of the parents who did attend found the workshop very hard for this very reason, and left early.

It was felt that the focus of the conference was sexual relationships and parenthood and that perhaps a future conference could cover other types of relationship such as friendship, relationship with support workers (this can be the most important relationship in a disabled person's life), and relationship with parents and carers (including growing away).

It was agreed that although some parents could not attend, the upside of holding the conference during working hours on a weekday was that so many people with a disability, and so many of the professionals who work with them were able to attend.

### **Barriers**

- Vulnerability of our children; fear that they might be abused, or hurt when things go wrong; fear of exploitation by others.

- We won't always be around, and have to trust others to protect our children.
- Fear that there may not be sufficient long-term support for our children.
- Lack of appropriate information, lack of sex education for people with learning disabilities.
- Concern about the level of training and support for frontline staff.
- Parents of daughters anxious about finding themselves bringing up unexpected grandchildren: we are an ageing population and may not be in a position to look after these children right through to adulthood.
- Siblings who worry about having children of their own and also about finding themselves committed to bringing up a disabled sibling's child.

### **Possible Solutions**

- We agreed that there is no blanket answer to all of these concerns.
- Person centred planning is essential.
- Support workers and parents and carers need to work together.
- Good information for everyone and appropriate sex education for people with learning disabilities.
- A commitment should be shown from the state to support people's rights and to help them shoulder their responsibilities.

## **The Managers' Perspective**

The "Managers" group consisted of people from a variety of organisations including statutory, voluntary and not for profit groups. The areas of responsibility covered were day care, community support, supported living and respite care.

### **Problems and barriers**

- There were several practical barriers identified. In a rural area transport is a major factor. If you are in a relationship getting to see your partner can be a major undertaking. A lack of one's own space leading to a lack of privacy is an issue; many people with a learning disability live in some kind of shared accommodation. A shortage of time and resources for support staff to interact in a meaningful way with service users around these issues. Of course more money would help with all of the above.
- There was agreement that the lack of education and skills around this subject was a stumbling block to achievement. Embarrassment and a lack of understanding lead to a lack of confidence. This was evident both for service users and for staff working with them. A lack of meaningful guidelines makes this situation worse, although it was acknowledged that we work with such a breadth of levels of learning disability this is a difficult area and that one size does not fit all.
- Fear of the whole subject, legal issues, past experiences, how society views relationships between people with a learning disability and the fact that parents and carers of all children, not just those with a learning disability, fear what will happen to their children are all barriers. These can lead to risk aversion and a reluctance to allow people to make mistakes.

- A lack of clarity around what is all right and who decides what is all right, in terms of relationships, appeared to be the main question to which managers required an answer.

## **Solutions discussed**

- There should be a proper policy/set of guidelines/ bill of rights to cover this area. It needs to be collective guidance and foster collective responsibility for all agencies involved. This should ensure consistency of approach and would be helped by proactive interaction amongst service providers. Organisations need to get together.
- Risk assessments should not be prohibitive. They should allow people to make mistakes in a safe way and then learn from those mistakes.
- If a more person centred approach was taken this may be a route to changing mindsets and fostering relationships in a more positive way.
- A toolkit of approaches should be compiled that would allow a variety of interventions with different people in different situations.
- People need to shed their preconceptions and build on today. There is a lot of good practice out there and experiences both good and bad should be shared. There was a feeling that we need to start from scratch to reinvigorate and formalise the whole process.

## **The Co-Chairs' Summary of the Day.**

The day ran smoothly. Everyone attending had plenty of opportunity to share and hear a variety of views, through discussion, drama, small group work, presentations and question and answer sessions.

The outcome at the end of the day was extremely positive. People with learning disabilities, parents and carers, managers and support staff were all united in wanting to achieve:

- Easily accessed effective support that empowers people to experience meaningful relationships throughout the course of their lives.
- A safe, but not restrictive environment for people to learn, develop and experience fulfilling relationships.
- A safe and supportive environment for people delivering services to operate within.
- A consistently applied policy.
- An unambiguous bill of rights and responsibilities.

**Our message as co-chairs of the day would be:**

**That all the information gathered on the day and collated in this report should be taken into full account and turned into action; it should not be allowed to 'hang in the air'.**

The phrases below were reproduced and displayed around the conference hall throughout the day to inspire and encourage the discussions.

“The greater the power the more dangerous the abuse”. Edmund Burke.

“We who say we serve have tremendous power over those we say we serve”. Dave Hingsburger.

“When we use the word “serve” I don’t think we often think of people with disabilities as our employers, we think of them as our raw ore, the skills we teach as our product and the behaviours we suppress as quality control. Their need gives us our power. Their vulnerability, our control. Their disability, our reason”. Dave Hingsburger.

“Powerlessness frustrates: absolute powerlessness frustrates absolutely. Absolute frustration is a dangerous emotion to run a world with”. Russel Baker.

“Our sense of power is more vivid when we break a spirit than when we win a heart”. Eric Hoffer.

“Power takes as ingratitude the writhing of its victim”. Rabindranath Tagore.

“A man is either free or not. There cannot be any apprenticeship for freedom”. Imamu Amiri Baraka

Someone once said “God save me from the people who want to save me from myself”

“It takes time to think. Now remember it may take a little longer when a person has a learning (cognitive) disability. So, they have another think coming, and they want to wait until it gets to the station”. Dave Hingsburger.

“A life spent in making mistakes is not only more honourable but more useful than a life spent doing nothing”. George Bernard Shaw.

“Recognise that your job isn't to craft people with disabilities into your own image. This will lead to frustration and to battles of will and power. You end up with the use of force. Simply recognizing that the only thing that's important is that people with disabilities discover their own way in the world, you can let go of a lot of frustration”. Dave Hingsburger.

## Summary of the Evaluation sheets

- 49% of the conference participants returned their evaluation sheets.

### Scores

- Publicity = 65%, Booking procedure = 69%, Information = 73%
- Speakers = 1<sup>st</sup> = 85% 2<sup>nd</sup> = 88%
- Opinion of the day = what you were hoping for? = 88%
- Venue = 74%

Comments were overwhelmingly positive:

"Really good day",

"It was cool seeing his girlfriend and the baby. Wish I was like that"

"Very helpful for me",

"Lovely conference"

"The day was excellent-drama was very good",

"Good to have presentations from someone with LD who has good experience",

"What an inspirational story and an inspirational young man. It was a pleasure to listen to him talk about his lovely family and a real breath of fresh air to hear his positive story"

“Inspirational!” “It has been a wonderful day”,

“Best part was time to discuss how it is and what is needed, time to discuss with a variety of people”.

“A very thought provoking day”

“Good that all concerned parties invited”

“An excellent day that raised many very relevant issues. Great company too!!”

### **Summary of the Perspectives from the Workshops.**

The record of the workshop discussions details the views expressed on the day. This summary draws together some of the clear messages. Contributions from all four workshops were thoughtful and detailed. The points raised and solutions discussed show a great deal of unanimity especially on support for person centred planning. It is fair to say that the points on the barriers for people raised in the learning disability group matched the points raised in all the groups. So we can say that everyone is aware of precisely what needs to change. Each group discussed the same practicalities ie transport issues; lack of personal space; time constraints; lack of clarity; risk aversion and most especially the need for good quality training and education.

The message from all four perspectives was that they endorsed the right to relationships. Further, that people should be appropriately supported to conduct their own relationships in the way that they choose.

The contributions from the support workers illustrated, with honesty, the many frustrations and challenges that they face in trying to deal with relationship issues. Their support for improving the lives of people, though, came through in the equally numerous suggestions for improvements in practice. Their main message was that they need more training; support and guidance.

The parents and carers group were concerned with emotional barriers; long term developments and consequences. They spoke of the need for staff and parents to work together. One of their proposals was that the state should show commitment to support people's rights and also their responsibilities.

Fear was a term that came up in the manager's group; the support workers group and the parents group as they discussed the anxieties around the subject. The learning disabilities group confronted these anxieties in their discussion about abuse in relationships with some participants recounting past experience of abusive relationships.

The lack of control in their lives was discussed as a major issue for people with learning disabilities. Having to rely on other people was seen as a key impediment to their developing relationships. Their final comment from the workshop was that they needed more information and more support.

The manager's group emerged with a set of proposals to build on the day. These were:

That a policy is needed to provide clarity; risk assessments should not be prohibitive so as to allow people to make mistakes in a safe environment and a toolkit of approaches needs to be developed on the basis of person centred planning.

## **Conclusions on the Day**

This report is a positive product from the day which we intend to share as widely as possible. We believe that it will be of interest to everyone who is involved in the lives of people with learning disabilities both in Ceredigion and also outside of the county.

It is clear that we achieved the aim of the day which was to promote a discussion about the topic of relationships for people with learning disabilities in Ceredigion which included everyone involved.

The collaborative model that we created worked well. The discussion of the views from each workshop session was conducted with everybody in the main room. People came together to hear the different points of view. It was refreshing and stimulating for the participants to hear the perspectives of others first hand.

An important outcome was achieved in that people were given an equal voice and a safe place to express it. Because of this we were able to take a 'snapshot' of what is happening in Ceredigion. We now have a record of what the representatives of the different perspectives are feeling and saying at this moment.

Participants stated that they were inspired by the day. We therefore want to build on the information that we have gathered to influence the development of policies on relationships for people with learning disabilities.

One important area that we made an attempt to discuss was raising the voice of the least able. It is fair to say this was only partially achieved. It was a difficult objective and will need some innovative thinking and perhaps more expertise in order to achieve this in a meaningful way.

## Recommendations

We recommend:

1. That this model of discussion is used and taken as good practice so that good communication is engendered and encouraged from all parties.
2. That clear policy and procedure guidance is written, **as a matter of urgency**, by each of the statutory authorities ie Health; Social Services and Education taking into account the information gathered from the day.
3. Those measures are put in place to ensure that all policy and procedure guidance are written to harmonise with each other. This is to ensure clarity for everyone concerned.
4. That the commitment to person centred planning be continued and strengthened.
5. That all staff contracts include the requirement to receive training and guidance in how to support social and sexual relationships for people with learning disabilities.
6. That all appropriate organisations commit to getting together, on a regular basis, to build on days, such as this one, to improve communication and build on good practice.

Finally

The conference day and this report were brought to fruition by the sterling efforts of, in alphabetical order:

Anne-Marie Carpenter, AWF Administrator; Kay Davies, Community LD Nurse; Pauline Heyes, Ceredigion KeyRing-Living support Networks; Non Jenkins, Ceredigion Parents and Carers Forum; Elis Jones, Director AWF; Andrew Kennard, Parent; Jan Kench, Eich Dewis Chi; Donna Martindale, Parent; Mike McCarthy, AWF Volunteer; Pat McCarthy, AWF Regional Officer; June Morley, Area Manager KeyRing Living support Networks; Jonathan Richards, Ceredigion People First; Claire Turner, Ceredigion People First; Gavin Wood, Manager Ceredigion Community Learning Disabilities Team and Pauline Young, AWF Chairperson.

Our special thanks to the Ceredigion People First Drama Group.