

Developing new guidance for parents with a learning disability: What do parents and professionals want to see?

A Report on Participation Sessions

Background

The Welsh Government wants to introduce guidance for statutory agencies on how best to support parents with a learning disability and to reconcile the need to safeguard a child with keeping families together. It recognised that the findings of the research report “*Being a Family*” commissioned from Learning Disability Wales and researched and written by Joyce Howarth, into the difficulties faced by parents with a learning disability in Wales required action.

Welsh Government accepted advice by Learning Disability Wales that the first step in writing the new guidance is to consult with parents and professionals on what the guidance should contain.

Purpose

Learning Disability Wales organised and facilitated two sessions to explore the issues identified in “*Being a Family*” and to gather views on what should be included in good practice guidance to be issued by the Welsh Government.

The sessions were attended by parents with learning disabilities (parents whose child was living with them and parents whose child had been taken into care), professionals from social services (children’s teams and adult teams) and third sector organisations that provide support and advocacy to parents with learning disabilities.

Method

Two participation sessions were arranged:

- Monday, 20 February 2012, 10am-3pm – Carmarthen
- Friday, 24 February 2012, 10am-3pm – Llandudno

Details of the sessions and their purpose were circulated widely to the 'Finding the Right Support' Network, that Learning Disability Wales has supported, to Social Service and Local Authority contacts, to Third Sector organisations providing support and advocacy to parents with learning disabilities and to other statutory sector contacts.

Facilitators were identified to assist Rebecca Watkins with the two sessions:

- Carmarthen – Karen Chandler, Pembrokeshire People First
- Llandudno – Angela Hughes and Julie Bray.

The way in which each participation session was conducted was varied to some extent to accommodate the preferences of each group and the approaches of the facilitators.

Carmarthen

The facilitators explained to the participants the purpose of the consultation, and how their contribution would be used to inform the best practice guidance that the Welsh Government will be developing.

Participants introduced themselves and contributed what as individuals they thought was important for parents,

Members from Pembrokeshire People First presented a drama based on the true, traumatic and troubling experiences that individual parents with a learning disability have sometimes faced. The group discussed the drama, considered whether it was accurate and representative, what issues were raised, what actions could have been put in place to give the scenario a different outcome and what lessons should be learnt.

In a practical and user friendly manner, participants were asked to individually consider the following questions and to share their thoughts about:

- What's working?
- What's not working?
- What should others (e.g. Local Authorities, Local Health Boards, statutory bodies) working with Parents with Learning Disabilities know?
- What do schools need to do?
- Who should work together?
- How would funding for more advocates help?

An overview of the individual responses was presented to the group as a whole and then the participants split into four groups. After lively discussion each group identified their top 3 points to consider when working with parents with a learning disability.

The session concluded with participants sharing information about their local experience of services and picked out examples where progress being made.

Llandudno

The facilitators again explained to the participants the purpose of the consultation, and how their contribution would be used to inform the best practice guidance that the Welsh Government will be developing.

Everyone introduced themselves and contributed what as individuals was important about being a parent.

Participants began by looking in groups at 'what was working' and 'what was not working' from the perspectives of parents with learning disabilities, and professionals.

Participants then identified their priorities from the list of 'What's Working?' and 'What's Not Working?' comments that had been produced by marking them with a 'dot'. The top two comments then became the focus for further group work. The groups considered what would success look like for each of the 'What's Working?' priorities and explored further the two 'What's Not Working?' statements.

Implications for Policy and Preparation of Guidance

A full record of feedback from each Participation Session is provided as Appendices 1 & 2.

Key Issues

In summary, the following key issues emerged from the participation sessions:

Communication

Communication between the parent with a learning disability and the professional should be:

- Clear, relevant and accessible
- Face to face
- Encouraging a two way dialogue
- Identifying what support is available
- Through the medium of Welsh if required

Implications to be considered by Welsh Government in Guidance:

- Professionals should be trained in communicating in an accessible and understandable manner
- Establishing a minimum level of support to be expected, so there is more consistency across Wales

Information

Information provided should:

- Include practical advice on parenting
- Be provided in accessible formats
- Identify support networks
- Be part of a clear and understandable process
- Be more consistent throughout Wales

Implications to be considered by Welsh Government in Guidance:

- Encouraging local agencies to agree what constitutes 'good enough' parenting ability and competence
- Encourage local agencies to help parents come together to learn, share and encourage each other

Education, training and support

The assistance given to parents should:

- Be available from the beginning and through the long-term
- Develop the 'what can be done' rather than focus on 'what can't'.
- Be developed by professionals who have received training from parents with a learning disability
- Utilise programmes like the 'Incredible Years'

Implications to be considered by Welsh Government in Guidance:

- Improve the accessibility and availability of sex education for people with a learning disability
- Encourage agencies to organise training for professionals that includes practical input from parents with a learning disability
- Encourage professionals to provide parenting training opportunities for parents with a learning disability

Joint working

Effective joint working helps:

- Sharing of information
- Makes it easier to identify a single liaison point for a parent with a learning disability
- The relevant professionals to consider and respond flexibly to the long-term support needs of the parent

Implications to be considered by Welsh Government in Guidance:

- A requirement for protocols to be in place in each local authority about how children's teams, learning disability teams and health professionals will collaborate to assist the parent with a learning disability
- That protocols recognise the importance of the parent being provided with a single professional liaison contact.
- That protocols recognise the importance of long-term proactive and preventative support in line with 'Fulfilled Lives, Supportive Communities.'

Advocacy

Access to advocacy by parents should be an:

- Independent service available to all parents
- Integral part of the support and assistance process available to parents.

Implications to be considered by Welsh Government in Guidance:

- That the usefulness of advocacy should always be considered when care and support plans for parents are being drawn up

- Local authorities are required to fund access to advocacy for parents if it is identified as a need.

Conclusion

It is very clear from the Appendices, Evaluations and the Closing Comments later on in the report that all the participants welcomed the opportunity to shape Welsh Government Guidance and engaged enthusiastically with each other at the sessions.

The overriding message that participants gave about the style of any final guidance that the Welsh Government issues is that it should be written simply, it should be an effective and practical guide for professionals while reassuring parents with a learning disability about the sort of support that they have the right to receive. It will be important if any guidance is to be effective that professionals are given a clear direction about their practice and that outcomes for parents with a learning disability are consistently monitored.

Learning Disability Wales

Acknowledgements

Learning Disability Wales wishes to thank the many individuals who gave up their time to travel to these participation sessions, to share experiences that in some instances were very personal and upsetting and to contribute to the findings of this report.

30 March 2012

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Appendix 1 – Feedback from Carmarthen Participation Session

What's working?	What's not working?
Communication	
<ol style="list-style-type: none"> 1. Listening to us 2. Communication – face-to-face, verbal, accessible 3. Treating individuals as individuals 4. Sense of humour 5. Being open minded 6. Not being infantilised/treated like people with a learning disability 7. Being honest with parents – direct but not offensive 8. Acknowledging that same things works for some and not for others – not “one size fits all” 	<ol style="list-style-type: none"> 1. Too many meetings at one time 2. Too many requests, parents become overwhelmed 3. All parties involved not communicating 4. People using jargon and long words 5. Judgemental people 6. Not being listened to! 7. Arguing 8. Having a social worker who doesn't speak English very well 9. If you have an attitude when you go into meetings, they won't listen 10. Overwhelming parents by using long words and long sentences in meetings 11. Constantly being negative! Never saying anything about what the parent is doing right
Information	
<ol style="list-style-type: none"> 1. Giving information in a way we understand 2. Making time to explain things – if a report is written, own it and explain it, don't just send it out 	<ol style="list-style-type: none"> 1. Reports not completed 2. People using jargon and long words 3. Lack of understanding of what goes on in a meeting. 4. Information complex, with no explanations 5. Using concepts instead of explaining what is needed – e.g. “home conditions need improving” rather than “tidy up and keep place clean”

Education, Training and Support	
<ol style="list-style-type: none"> 1. No assumptions 2. Acceptance of different ways to live/standards 3. Non-judgemental attitudes 4. Training and understanding of learning disabilities for all professionals involved including childcare team and health. 5. Developing specific resources to support parents with a learning disability. 6. Supported lodging for parents/children/LAC and young people with learning disabilities. 	<ol style="list-style-type: none"> 1. Having no support while I was pregnant 2. Lack of groups where parents can support each other
Joint Working	
<ol style="list-style-type: none"> 1. Working together 2. A good, understanding solicitor 3. Own social worker from Learning Disability Team 4. Joined up working – Learning Disability Team and children's services working together 5. Support networks e.g. Family Circle, Tros Gynnal 6. Community support (links in the community) 7. Family Circle involvement 8. Parent and child groups – integrated ones – helps build networks, links and parents with a learning disability feel that they are not the only ones – everyone has the same struggles with parenthood. 	<ol style="list-style-type: none"> 1. Too many organisations being involved 2. Not being clear about boundaries 3. Overwhelming parents with a stream of different people with different roles – a balance is needed! 4. People passing the buck – if it's your role and remit – do it! 5. People working in isolation
Advocacy	
<ol style="list-style-type: none"> 1. Independent advocacy 2. Having an advocate to help explain what professionals mean and to get our views across 	<ol style="list-style-type: none"> 1. Limited funding/ funding ending

Miscellaneous

- | | |
|--|---|
| <ol style="list-style-type: none"> 1. Acknowledging that parenting is difficult for everyone. 2. Residential assessment (Orchard House) 3. "PAM" (parenting assessment module) [varying opinions as to whether this works] 4. "Adult placement carer" placements for mother and baby – nurturing, educating, supporting (needs special kind of foster carer) | <ol style="list-style-type: none"> 1. Overwhelming parents with long "contracts of expectation" 2. Fostering stops at 18 – what then? Where's the support? Parenting is a lifetime job, not just until 18! 3. People not sticking to their end of the deal – not doing what they said they would and when 4. Having too many expectations 5. Rurality – long distances leading to isolation 6. Not addressing (child) poverty issues 7. Limited variety of assessments |
|--|---|

What should others (e.g. Local Authorities, Local Health Boards, statutory bodies) working with Parents with Learning Disabilities know?

- How to communicate
- Take time
- What is "good enough" parenting
- Easy read – pictures, not big words
- Bite-sized pieces
- "Can do" not "can't do"
- Copy stuff to support worker as well
- Individual communication
- Working together with each other
- Active listening
- Many people don't understand widget
- Partnership works
- Inter-agency working
- More support for parents in the home
- Parents can feel scared of saying what they feel because of the fear of losing their children, of being judged
- Parents with a learning disability are often given different messages by different professionals
- Insensitive and confusing intervention erodes self-confidence and does not make good parents
- People can learn by example. Investment in peer support from other families can create better learning opportunities and help the family thrive

How would funding for more advocates help?

- Yes please!
- Advocates help us know what people mean so we can put our views across
- Guaranteed funding = more security = better results for parents
- Support groups – parents’ groups – self-advocacy
- Give support at meetings with social workers, with solicitors, and at court
- Reaching/ supporting more people
- More people could get their voices heard and understand what is going on better
- Advocates also work as co-ordinators to help develop inter-agency working
- Help link services and service users
- Early intervention – prevents problems later
- Advocates help clients understand what social services want – saves cost of foster care
- Advocates can help you to understand a difficult and complex process
- Advocates can meet social workers and explain a person’s views
- More knowledge of what is available is also important
- Permanent posts would ensure long-term support from someone the family really gets to know
- Focus on developing broadly based community/ peer/ family advocacy/mentoring
- Adult and child teams have their own remits and own priorities set. Advocates are independent and can help parents speak about their priorities, wants, needs etc., offer and negotiate with all involved to move forward in a positive way.

What do schools need to do?

- Better sex education – needs to be inclusive
- Information around diversity – “vive la difference”!
- Parenting lessons
- 1:1 support for children with learning disabilities
- Easy read/ accessible info for letters and correspondence to parents
- Be more supportive to the children and recognise family difficulties and their effects
- Set up support groups for parents
- Bring in drama to understand/ teach children about learning disabilities
- Employ home-school liaison officers who have time to visit home and talk to parents and support them in meetings in school
- Transition assistance appropriate and needed

- Budgeting lessons
- Focus on families as well as pupils
- Give the child the right support
- As well as sex education, relationship education – what is a good or a difficult relationship?
- Sex education should be compulsory at special schools and in “special needs classes”
- Less division/ separation between students with a learning disability and without – this would raise awareness and acceptance and show there’s not much difference/ we all face the same issues
- Meet with parents more regularly

Who should work together?

- Children and adult services
- Health and adult and children’s services
- Schools with SSD
- Advocates who are independent
- Everybody with an interest
- Voluntary sector
- Health board
- Housing organisations
- Homestart or similar
- Midwives
- Health visitors
- Family
- Solicitors
- GPs
- ALL services – to ensure all information is in a format the individual understands – meetings, appointments, minutes, reports etc.

How can we make joint working happen?

- Let the parents train them to see what we put up with
- Keyworker – specified stand-alone role – with authority to co-ordinate multi-disciplinary team working
- Legislation so each department has a designated representative that is committed to working with the keyworker
- Regular meetings between different teams to talk about ways to work together

- and help promote understanding of each teams' role/ priorities
- All agencies to inform advocates of dates of meetings, copies of info, minutes, and meet advocates regularly to update and check parents understand info – advocates get consent from parents and share/ request help directly from agencies.

3 Priorities for working with a Parent with a Learning Disability

Group 1

1. Parents with a learning disability train support workers and social workers, improving their understanding and awareness.
2. Information readily available about the support groups available for parents with a learning disability.
3. Good communication – parents with a learning disability informed about what is happening throughout every step of the process and why.

Group 2

1. Communication – social workers talk 'your language'. Communicate in whatever way is best for the parent.
2. Holistic Approach to family – looking at family as a unit and understanding learning needs may be very different.
3. Robust funding for independent advocacy.

Group 3

1. Communication – language of choice and easy to read.
2. Parent with a learning disability involved in training to raise awareness and improve understanding of people who are working with them.
3. Circles of support – professionals, communities, families.

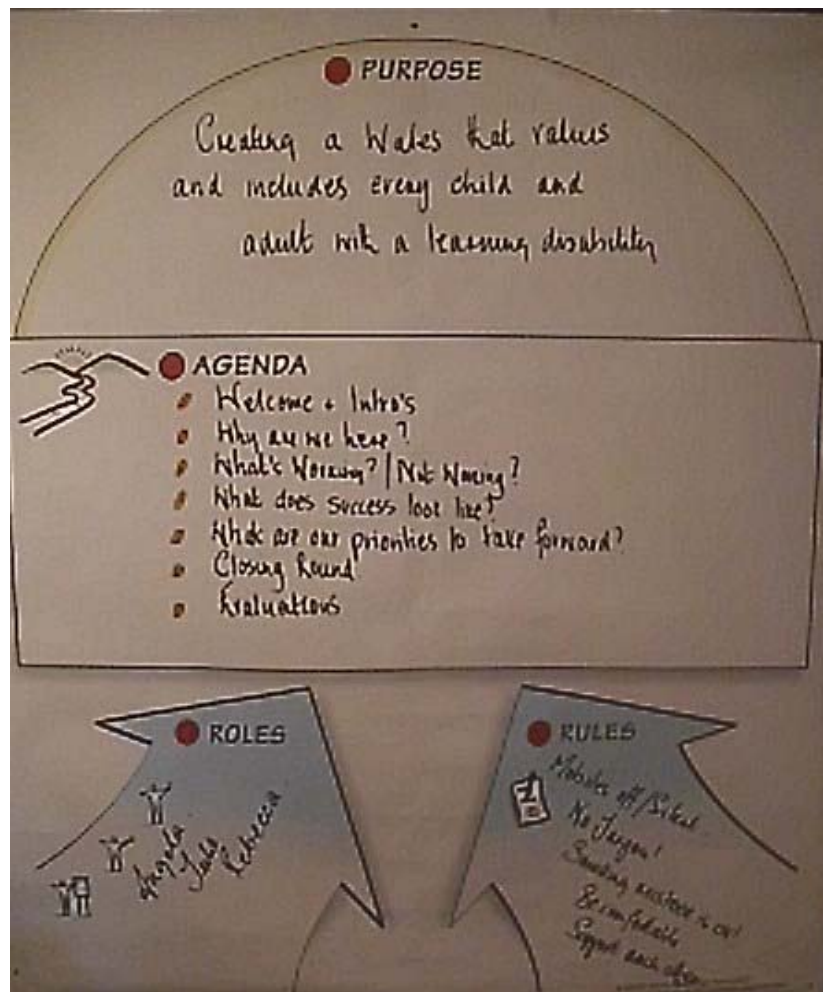
Group 4

1. Training delivered to parents with a learning disability for better understanding.
2. More access to advocacy and information e.g. Rights and law.
3. Consistency of policy across Wales with "teeth".

Quote from Parent at Carmarthen session:

"I am a parent with a learning disability. I have a child who is nearly 3 years old. When my baby was born, nobody asked me what I wanted for my child. Today is the first time that anybody has asked me about what I think about what should have happened to my child. I will always be her mum, won't I?"

Appendix 2 – Feedback from Llandudno Participation Session



‘What’s working & Not working?’ currently for Parents with Learning Disability

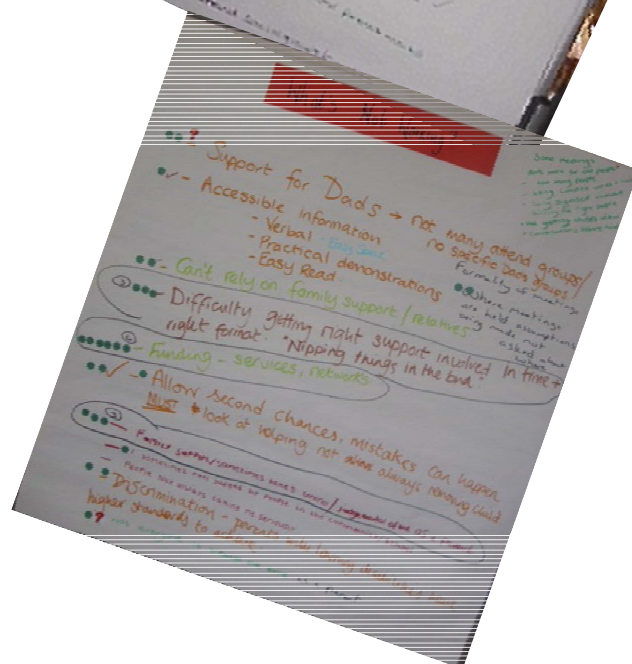
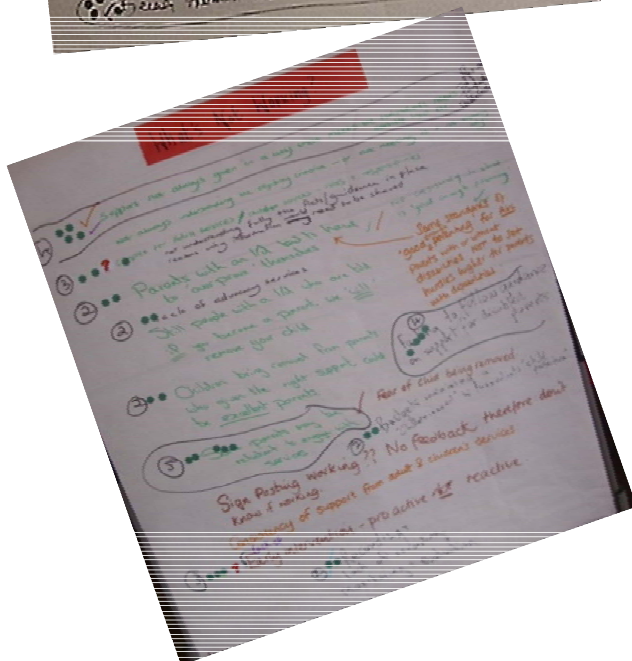
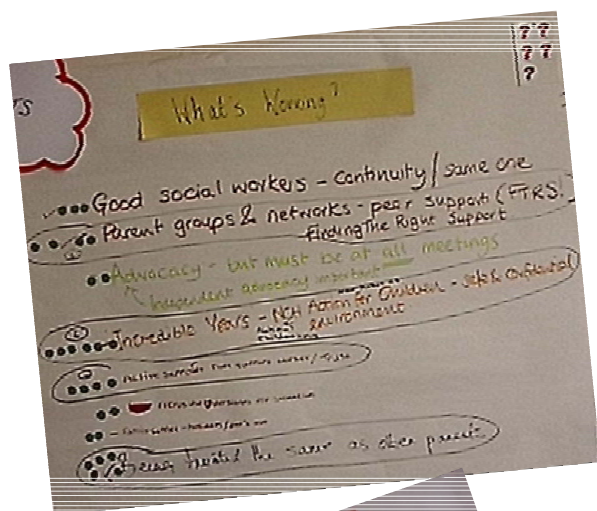
What’s working?	What’s not working?
Communication	
1. Being treated the same as other parents	1. Family support sometimes takes control and judgemental of me as a parent 2. People not always taking me seriously 3. I sometimes feel judged by people in the community and school 4. Formality of meetings 5. Not everyone is treated the same as a parent 6. Using complex words and information
Information	
	1. Accessible information – verbal (easy speak), practical demonstrations, easy read.
Education, Training and Support	
1. Incredible Years – Action for Children, safe and confidential environment 2. Active support from support workers and mutual trust	1. Support for Dad’s – not many attending groups/no specific Dad’s groups 2. Difficulty getting right support involved in time, and in the right format ‘nipping things in the bud’ 3. Allow second chances, mistakes can happen. MUST look at helping, not always involving the child
Joint Working	
1. Good social worker – continuity/same one 2. Parent groups and networks – peer support, Finding The Right	1. Some meetings don’t work for all people – too many people 2. Meetings being organised without involving the right people

Support (FTRS) 3. Family support – holidays and days out	3. Not getting the child's view 4. Conversations taking place beforehand, not including all
Advocacy	
1. Advocacy – but must be at all meetings, independent advocacy important.	1. Funding
Miscellaneous	
1. Friends who understand my situation	1. Can't rely on family support/relatives 2. Funding – services, networks 3. Discrimination – parents with learning disabilities have higher standards to achieve

‘What’s working & Not working?’ currently for Professionals

What’s working?	What’s not working?
Communication	
1. Attitudes changing for the better 2. More focus in media around parents with a learning disability	1. Still people with a learning disability that are told – ‘if you become a parent, we will remove your child!’ 2. Some parents may be reluctant to engage with services, fear of child being removed 3.
Information	
1. Signposting	1. Not always understanding eligibility criteria – or not meeting it and not knowing why. 2. Recording – lack of recording, monitoring and evaluation. 3. Signposting working??? No feedback, therefore we don't know if it is working.

Education, Training and Support	
<ol style="list-style-type: none"> 1. Every case/family to be looked at and assessed individually 2. Active support 3. Opportunities to attend social groups and networks 	<ol style="list-style-type: none"> 1. Support not always given in a way that meets the individual's needs, e.g. accessible information 2. Children being removed from parents, who if given the right support could be excellent parents. 3. Lack of early intervention – proactive NOT reactive! 4.
Joint Working	
<ol style="list-style-type: none"> 1. Better communication between Adult Services and Children's Services (but there is still work to do!!) 2. Conwy & Gwynedd – more referrals from children's team to adult services, joint working (not working in isolation from each other) 	<ol style="list-style-type: none"> 1. Roles and responsibilities – complex for adult services/children's services, not understanding fully the Act/Guidance's in place and reasons why information would need to be shared. 2. Consistency of support from adult and children's services. 3. Failing to follow guidance on support for disabled parents 4.
Advocacy	
<ol style="list-style-type: none"> 1. Advocacy 	<ol style="list-style-type: none"> 1. Lack of advocacy services
Miscellaneous	
	<ol style="list-style-type: none"> 1. People with a learning disability tend to have to 'over prove' themselves – not to set hurdles higher for parents with disabilities – same standards of 'good enough parenting' for ALL parents, with or without disabilities! 2. Budgets meaning a 'children in need' is turned into a 'child protection!'



Priority area identified for Parents with Learning Disability

What's working?	What's not working?
1. Incredible Years – Action for Children, safe & confidential environment	2. Funding – services, networks

Priority area identified for Professionals

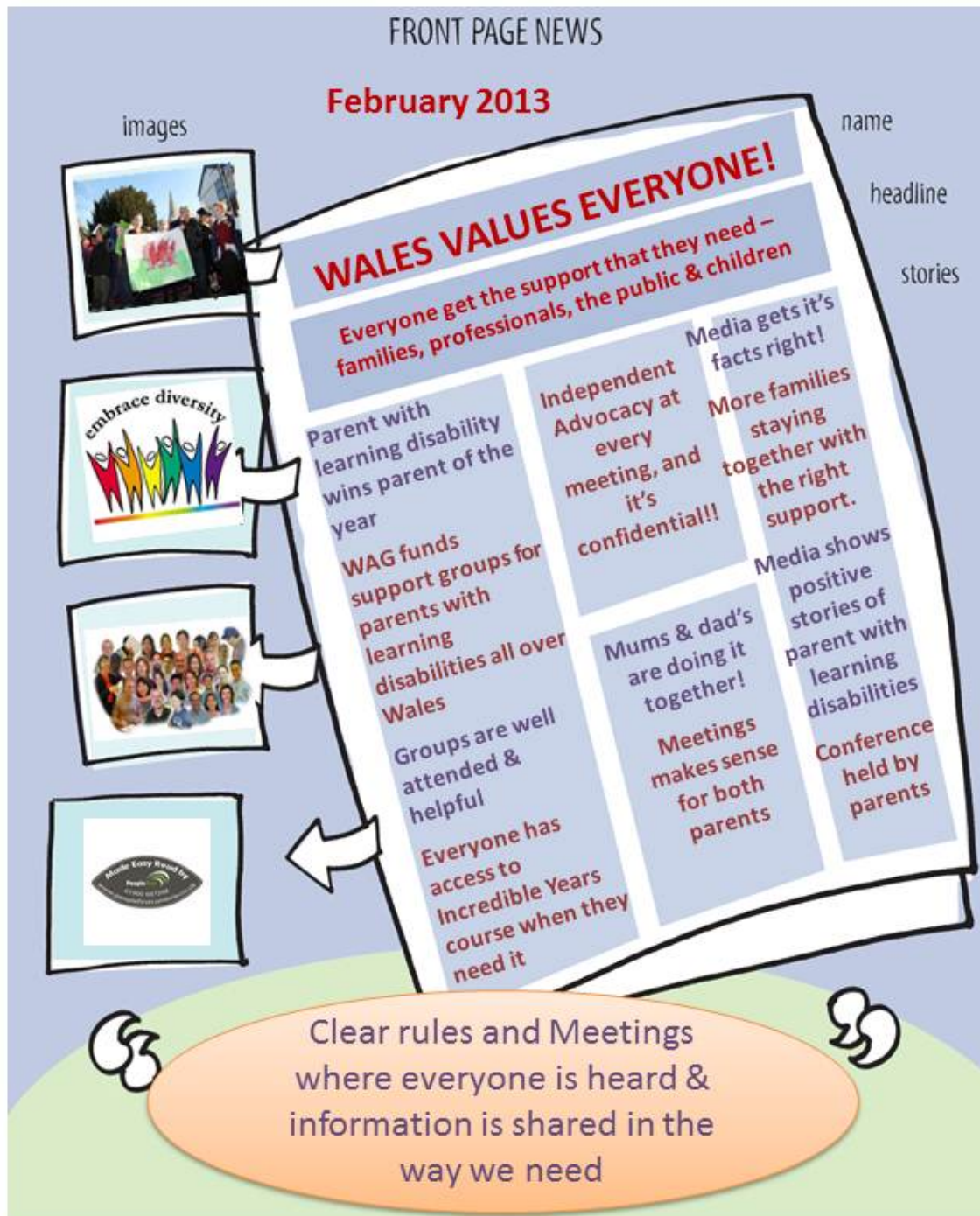
What's working?	What's not working?
1. Better communication between Adult Services and Children's Services (but there is still work to do!!)	2. Some parents may be reluctant to engage with services, fear of child being removed

Given what we now know, what would success look like for each of the 'what's working' statements in 12 months

'Incredible Years – Action for Children, safe & confidential environment'

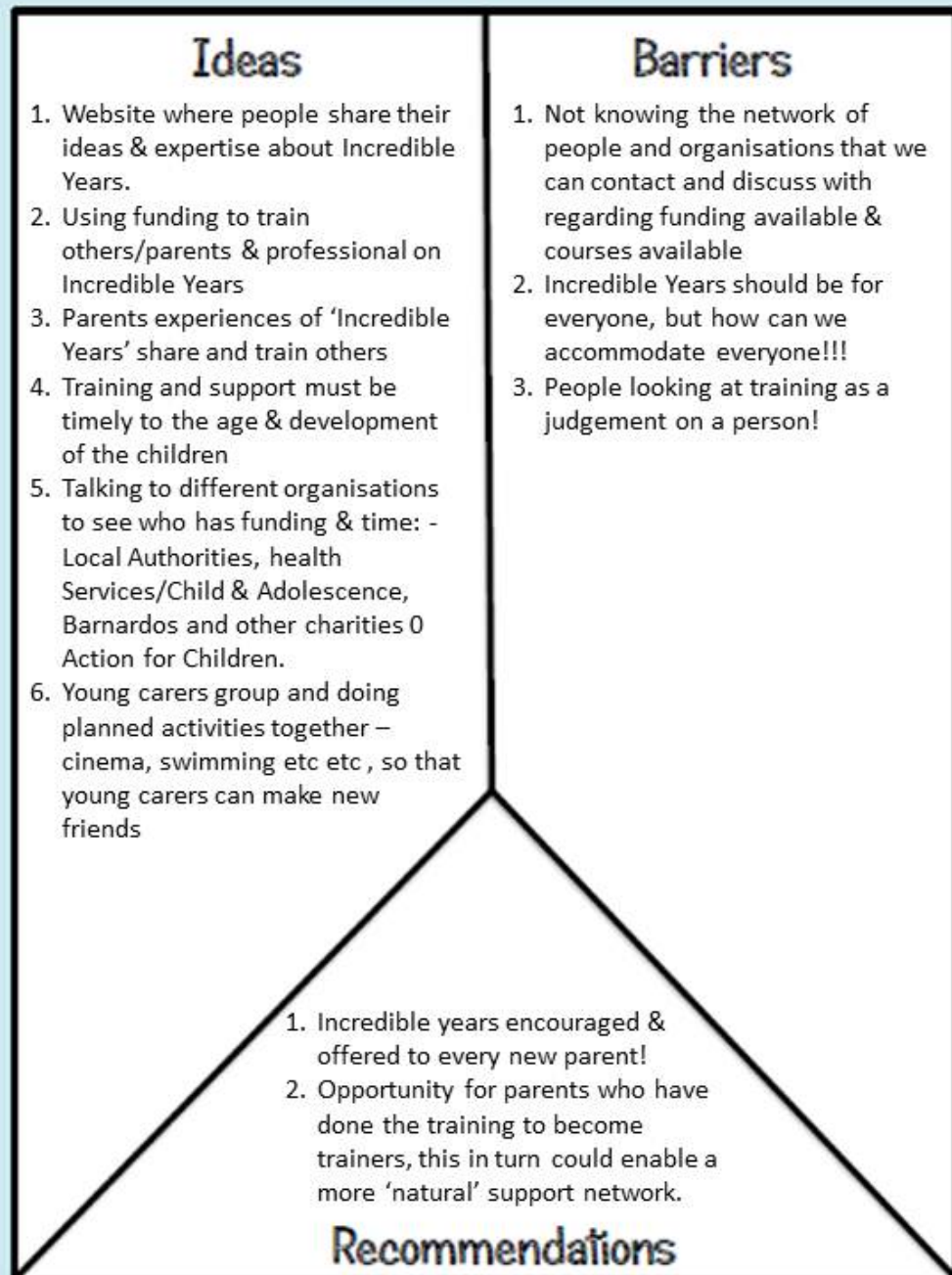


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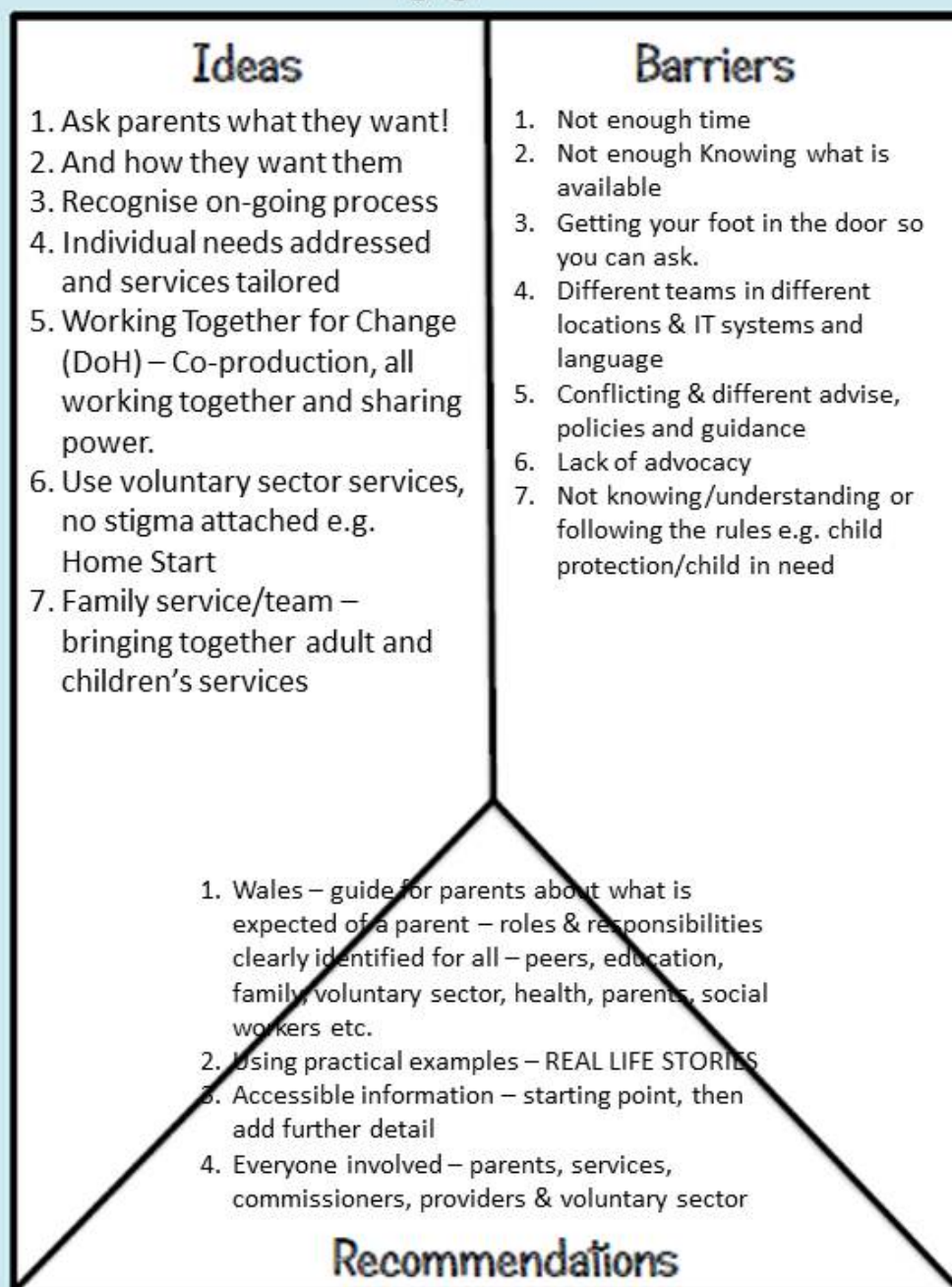


The 'Y Frames' exercise was then used to explore the top 2 identified as 'not working'.

How can we be creative with funding, services and networks?



How to provide services parents want to engage with?



Some closing comments about the consultation day:



- || I felt more confident with professionals – it was an even platform.
- || It was great hearing about the experiences of parents, and as a professional I have learnt so much today, thank you!
- || Very good day, there were different perspectives and good ideas.
- || Networking and meeting others, it's an excellent place to start with a new idea.
- || Meeting others
- || Exciting being with others who want to change things!
- || Hearing stories from parents and professionals, and having good conversations
- || Shared values, and I'm very enthused!

Appendix 3 – Summary of Evaluation Responses & Equal Opportunities Monitoring

Summary of Evaluation Responses and Comments completed for each event

	Carmarthen	Llandudno
1. Was the event...		
Very Good	74%	75%
Good	26	25
O.K.	0	0
Poor	0	0
Bad	0	0

2. What did you think about the drama?		
Very Good	90	N/A
Good	10	N/A
O.K.	0	N/A
Poor	0	N/A
Bad	0	N/A
Comments: <ul style="list-style-type: none"> • I think drama can be an effective way to share stories/start discussions. • Powerful, because it was based on a true story. • Concerning to see no one was shocked. • A very powerful tool to show how the issue affects parents. • Touched on something unfortunately very common. • Really good. • Very good input. 		

3. What did you think of the group work?		
Very Good	90	75
Good	10	25
O.K.	0	0
Poor	0	0
Bad	0	0
Comments:	<ul style="list-style-type: none"> ▪ It was a really involved, active group and I think we got a lot done. Lots of ideas. ▪ Loved interacting with different people. ▪ Lots of important ideas of how to improve things. ▪ Message needs to go back to the Welsh Govt. 	<ul style="list-style-type: none"> ▪ Was good to share ideas and challenge one another's perception in a healthy way. ▪ It was a very interesting day. ▪ It would have been good to have more parents and more colleagues from children's services

	and parents need support early.	▪ Very inspiring session.
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4. Any other comments?

Carmarthen:

- I think more senior staff from health and social services need to be involved in this.
- We supported a parent to attend the event and she found it useful. We also found it invaluable that she was able to share her experiences.
- I hope the Welsh Government listen to the recommendations!
- Parking was a problem. Parent had to walk a long way over rough ground. Brought parent who engaged well at event.
- Lovely place for meetings and training
- Excellent way to produce a range of very relevant views and information.
- The group/consultation was well run and facilitated. I really hope the government take on board the information shared.

Llandudno

- Good meeting
- Course very useful and interesting thank you. Would it be possible to have other course members contact details to network. Venue slightly disappointing. No parking, having to Pay for Parking and not knowing about this. Tea very weak!! Lunch lovely thanks.
- Really interesting event – thank you. Looking forward to receiving feedback.

Summary of Equal Opportunities Monitoring completed.

1. Are you ...	
Male	0%
Female	100%

2. How old are you?	
16-25	12%
26-35	27%
36-45	23%
46-55	27%
56-65	11%

3. How would you describe your ethnic origin?	
British	62%
English	3%
Welsh	35%

4. Do you consider yourself disabled?	
Yes	4%
No	85%
Prefer not to say	11%

5. How would you describe your sexuality?	
Heterosexual	69%
Lesbian/Gay Woman	4%
Other	4%
Prefer not to say	23%

6. What is your religion or belief?	
Christian	38%
None	30%
Prefer not to say	28%
Other – Universal	4%

7. What is your first language?	
Welsh	8%
English	92%