

West Dunbartonshire Learning Disabilities services

Report on

Learning Disability Service User Consultation

21st November 2013

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Introduction

West Dunbartonshire Council held its sixth annual Learning Disability Consultation Event for Service Users in Dumbarton Burgh Hall on 21st November 2013. Simultaneously a carers consultation was carried out. The details of this can be seen in the Carers Report.

The overall theme for the day was *Making Choices Making Changes*.

Background

The theme was chosen from the results of the 2012 survey of those who use learning disability services. Service users were sent questionnaires asking what they thought of the supports they received. Whilst over 90% expressed satisfaction with the support they receive, some wanted to learn more about how they could have even more choice about their supports, and how to change these if they wished (appendix 1).

Service providers were allocated a number of places for their service users, this was calculated proportionate to the number of service users accessing their service on that particular day. The services received an invitation letter (appendix 2) and poster (appendix 3) along with application forms (appendix 4) to gather the service users' details.

Forty facilitators were involved on the day. Sixteen of these facilitators were allocated to one of seven tables to help with group discussion. Most facilitators were briefed in training for an hour the week before the Consultation, and given hand-outs and guidance explaining the format (appendix 5). During this it was decided who would be facilitating with discussion, reception/registration, photographers, kitchen and general support.

Outline of day

Service users were invited to attend either the morning or afternoon session. Carers also attended the morning session to give them some background for their afternoon discussion. Everyone was given a copy of the programme (appendix 6). These sessions were the same in their content and featured the Good Life Group acting out a series of 3 scenarios (appendix 8).

These illustrated the types of situations that service users may come across when accessing a service. Each scene finished with the actor saying they were “no happy”. The audience were then invited to discuss the issues raised by the performances, with help from facilitators.

Feedback was gathered in many ways:

- Discussion were recorded on flip-charts
- A thought board was available to write on the whole day, with a facilitator there to help take comments.
- Talking mats and pictorial supports were used to gather peoples' answers, and recorded through observations and photographs.

Special Considerations

In order to help those participants who have communication needs some materials were provided for facilitators to make use of. This was with the aim of being able to involve everyone in consultation. There were two specific tables for those who have difficulty expressing themselves verbally. Here we used Talking Mats an established method of gathering people's opinions using visuals.

Consideration to the layout and set up of the room was given in order to promote the audiences ability to see and hear the Good Life Group's Scenarios (see appendix 7 for layout).

Conclusion

The information collected during the consultation was qualitative, in that no figures were gathered to provide evidence of outcome. Instead, observations and comments were taken to gather results (appendix 9). It was felt that the service users benefitted from the scenarios as they engaged people and provoked thought and discussion. Some service users were able to identify with the characters in how they felt and could relate to their own experiences. The discussion centred on how people could affect change. An important factor in being able to make a change is having the knowledge of who to talk to, or who to get help from if you are unhappy with something. Most service users were able to identify people involved in their life or care who they could speak to. This would be the first step in being able to make change. Most of these service users were able to say if they felt they could talk about their problems to those people identified. Even though attempts were made to involve all service users in consultation, some were unable to participate in the consultation as it demanded a certain level of language based ability. For those service users the outcome of the day was limited which suggests consultation needs to be carried out differently. However the number of those attending and willing to participate in consultation is positive and highlights that given appropriate methods consultation could be carried out with these service users

The Consultation raises the agenda for services to have on going consultation with their service users. Involving clients in decisions made about their care and collecting regular feedback is important to see that they are receiving a service that they are happy with. In an attempt to carry out meaningful and successful consultation the service needs to consider the individual's needs and how they can participate in consultation in a way suited to them. One method of consultation does not work for everyone. It would be useful to have regular service user satisfaction survey, this could be carried out at a service user's review, or at a time deemed appropriate by the service.

Through discussions it was also apparent that some service users felt they were not always given opportunities or choices in their activities. This highlights the need for a 'person centred' approach, where carers and professionals listen more and actively support that person in achieving their goals.

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Appendix 1 – Service Users Satisfaction Survey Results

Results of Service User Satisfaction Survey September/October 2012					
	Yes	Not Sure	No	Not Completed	Total
Question 1.					
Do you have a say in the support services you get?	104	9	4		117
Question 2.					
a. Are you happy with your support?	114	2	1		117
b. Are you happy with your staff?	112	2	1	2	117
Question 3.					
Do staff ask you what you like or want to do?	113	2	2		117
Question 4.					
Do staff help you to get out and go to the places you want to go?	107	4	4	2	117
Question 5.					
Do you feel safe at the service you use?	114	2		1	117
Question 6.					
Do you have enough information about the service you use?	96	17	3	1	117
Question 7.					
Do you know how to make a complaint about your service?	81	16	20		117
Question 8.					
Is there anything else you want to tell us about the service?					
Comments					
"No" happy with the service					
A lot , but no-one seems to listen to me.					
All very nice and helpful					
Ann feels she has great fun while with NNs staff and can choose what ever she wants to do while on support					
Anne thinks the centre is good					
Dalmuir Locality staff are brilliant. They listen to what I say.					
Enjoy coming to Dumbarton Centre					
Fiona likes the service very much and the variety of activities offered					
Happy with the centre					
I am happy and like living in my house. I am not far from the shopping centre					
I am happy with my support					
I am happy with the staff I have got. Sometimes they have to move on and you've got to accept that.					

I am happy with the support I receive
I am quite happy with the service I get, although I would like to be able to pick other days. (Service not always that flexible)
I am very happy with the support I get at home.
I am very pleased with the way my son gets treated at RNIB. (Mother Annette Anderson)
I have a great social life and am always out and about. When I'm at home I enjoy having foot spas and listening to music. I also enjoy the company of my co-tenant.
I like being a member of Neighbourhood Networks. We have ideas to do different things.
I like coming out
I like coming to the centre to say hello and then I like to go out in the community
I like Cornerstone and the activities
I like it
I like male and female staff. I like it. You get good things.
I like meeting different people from different networks and going places.
I like the group I am in. It's the first time I ever been in a group like this.
I like the office and the staff.
I like the way things are and not rushed to decide what I want to do. Always helpful.
I like things the way they are
I like walking about and buses
I live with my friend Betty. I like my house.
I think Dumbarton Centre is nice. I'm still happy at Dumbarton Centre. I like to be happy.
I think it is a good service
I want to go shopping to Clydebank
I would like to get the bus from Faifley to Clydebank to Dalmuir by myself.
I'm out and about all the time and have a great social life. I also enjoy relaxing in front of the TV watching all the soaps. I enjoy the company of my co-tenant.
Is very happy with the service
It good because I go out and I am able to relax on a Friday.
It has changed my life and now I get out and about meeting people instead of sitting in the house.
It's alright - OK.
It's alright. I am thinking of new ideas for the centre, then I will tell Julie what they are and Anne Scott
It's brilliant, all the girls are brilliant as well as Scott.
It's fab
It's fine
It's good
It's great fun and I can choose where I want to go.
It's nice.
Lyn is a nice person to work with because she helps me.
My support at home is good.
New people carrier please. Longer slot time to go further
No. I do like it.
Outreach carer excellent
Rather be out and about. I explained how to make a complaint.
RNIB help me a lot

That it is a fantastic respite and wouldn't go anywhere else.
The centre is nice and I enjoy it.
They've helped me get my house the way I want it. Decorating, etc
This is good
This is my dream and that Dalmuir Locality is a very successful place to be in.
Thumbs up
To go out more
Very attentive

Summary

Organisation	Forms returned
Cornerstone Day Service	13
Cornerstone Home Care	1
Cornerstone Housing Support	6
Dalmuir Locality	18
Dumbarton Centre	23
Housing Support Services	3
Key Housing	15
Neighbourhood Network	14
Neighbourhood Networks Scotland	9
Respite Dunn Street	1
RNIB	14
Total	117

Number of forms sent

380

Appendix 2 – Invitation



West Dunbartonshire
Community Health Partnership



Learning Disability Services

Beardmore Business Centre
9 Beardmore Street
Dalmuir
CLYDEBANK G81 4HA
Direct Line: 0141 562 2324
Fax: 0141 562 2323

Date: 20/09/2013

Dear

West Dunbartonshire Council Learning Disability Services are hosting a Consultation Event on Thursday 21st November 2013. This year's event will be "Making Choices/ Making Changes". The morning session will run from 10.00 a.m. – 12.00 p.m. and the afternoon session from 1.00 p.m. – 3.00 p.m. at Dumbarton Burgh Hall. People can choose to come either morning or afternoon. Please indicate on the attached form which session you wish to attend. This event is for service users and will include drama scenarios and discussion groups.

Due to the places being limited, we have allocated **places** to your service. If you require more places please don't hesitate to contact us.

We have enclosed a poster advertising the day can you please ensure that it is displayed in a prominent place.

Please can you complete the attached forms and return to the above address confirming who will be attending, which session they will be present at and if they require support by Monday 28th October 2013.

Yours sincerely

David G. Elliott
General Manager

Appendix 3 - Poster

Learning Disability Consultation Day



**Can you tell people
what you want?**



**Do you know what to
do if things go wrong?**



Find out how:-

**Come to the Learning Disability
Consultation Day in Dumbarton
Burgh Hall on Thursday 21st
November 2013.**



**You can come in the morning
(10.00 a.m.—12.00 p.m.)**



**Or you can come in the afternoon
(1.00 p.m.—3.00 p.m.)**

Learning Disability Consultation Day
Thursday 21st November 2013
Application Form

Your name: _____
Your address: _____

Contact telephone number: _____

Which session will you be attending?

10.00 a.m. Morning Session 1.00 p.m. Afternoon Session

Will you be bringing someone to support you?

Yes No

Please return this to: Business Business Centre
8 Buchanan Street
Dumbarton
G81 1JH

By Friday 1st November 2013

**If you want to come, fill in the
form**

Appendix 4 – Application Form

**Learning Disability Consultation Day
21st November 2013
Application Form**



Your name:



Your address:



Contact telephone
number:

Which session will you be attending?



10.00 a.m.

Morning Session



1.00 p.m.

Afternoon Session



Will you be bringing someone to support you?

Yes

No

Please return this to: **Beardmore Business Centre
9 Beardmore Street
Dalmuir
G81 4HA**

By: Friday 1st November 2013

Appendix 5 – Facilitators Information

Consultation Day Planning

General Summary

1. The actor will finish their scene on ‘Am no happy!’ and will then Head facilitator (Sally) will begin a whole group discussion (see the example below).
2. The table discussions will then begin, whereby the table facilitators will gather the service users’ opinions and experiences, and record their understanding. They will **start by summarising** what just happened in the scene (provided with the written scenarios). The table facilitators must **decide who is in charge of leading the group and who will take notes**. They then will **ask a set of questions** to spark discussion.
3. The head facilitator will give some feedback to the group (collected during the table discussions) and introduce the next scene.

This will happen 3 times – for each scene

It is important that the table facilitators **pay attention** to the group discussion as they will need to summarise it for the group before beginning the discussion and can use the ideas/suggestions. It is very important that they **record the information people give on the table-top-flip-chart-boards**.

Example of Group Discussion

1. Why is _____ not happy? What happened?
2. How does _____ feel? (*referring to both characters: the service user and the carer*)
3. What should she do? Who should she talk to? *‘Experts’ will step in to help if no one participates.*

Ask the characters questions if the audience is not participating

1. How do you feel?

Table Discussions

Each discussion asks very similar questions. These are just a guide. Facilitators will need to ‘think on the spot’ when it comes to breaking questions down/changing the wording to help participants understanding.

Scene 1: Swimming

1. Has anything like that happened to you?
2. How did _____ feel? Have you ever felt like that?
3. Have you ever wanted to do something but you couldn't? *(Break it down to make it easier for the service user to tell their story)*
 - What was it?
 - Why couldn't you do it?
 - What did you do?
4. What could you do if this happened to you?
5. Who would you tell? Who could help you?

Scene 2: College

1. Has anything like that happened to you?
2. How did _____ feel? Have you ever felt like that?
3. Did you ever want to go somewhere but you were stopped? Did you ever want to learn something new but wasn't given a chance? *(Break it down to make it easier for the service user to tell their story)*
 - What was it?
 - Why couldn't you do it?
 - What did you do?
4. Why do you think _____'s dad said he wasn't allowed? *(to bring up the idea that they were just looking out for the person)*
5. What could you do if this happened to you?
6. Who would you tell? Who could help you?

Scene 3: Meeting with Worker

1. Has anything like that happened to you?
2. How did _____ feel? Have you ever felt like that?
3. Has a worker ever cancelled on you?
4. Has a worker ever been late to a meeting with you?
5. Has a worker ever went away too quick?
 - What happened? Why? What did you do?
6. What could you do if this happened to you?
7. Who would you tell? Who could help you?

General Tips for Facilitators

- If the service user talks about something unrelated bring them back to the topic: *remember we are talking about....*
- If someone keeps talking and doesn't give others a turn: *Ok (name), that's really good but I think we should let someone else speak for a bit. Or Now it's (name)'s turn to speak.*
- If the service user is giving unrelated answers: try wording the question differently, emphasise the question word more, e.g. *why* couldn't you? *What* did you do?
- Use the visual supports in any way you can think of to get a better idea of the service users' opinions, e.g. hold up the symbol for social worker and ask "who would ask help from their social worker?" ...if someone is struggling to say how they felt then show them the various emotions and they can choose a picture.

Appendix 6 – Programme



West Dunbartonshire Learning Disability Services Consultation Event Thursday 21st November 2013, Burgh Hall, Dumbarton

Morning Session

PROGRAMME

- 9.30 a.m. – 10.00 a.m. - Registration, tea and Coffee**
- 10.00 a.m. – 10.15 a.m. - Opening Remarks**
- 10.15 a.m. – 11.00 a.m. - Good life Group & Discussion**
- 11.00a.m. – 11.15 a.m. - Comfort Break**
- 11.15 a.m. – 11.45 a.m. - Good life Group & Discussion**
- 11.45 a.m.– 12.00 p.m. - Closing Remarks**

**West Dunbartonshire Learning Disability Services
Consultation Event Thursday 21st November 2013,
Burgh Hall, Dumbarton**

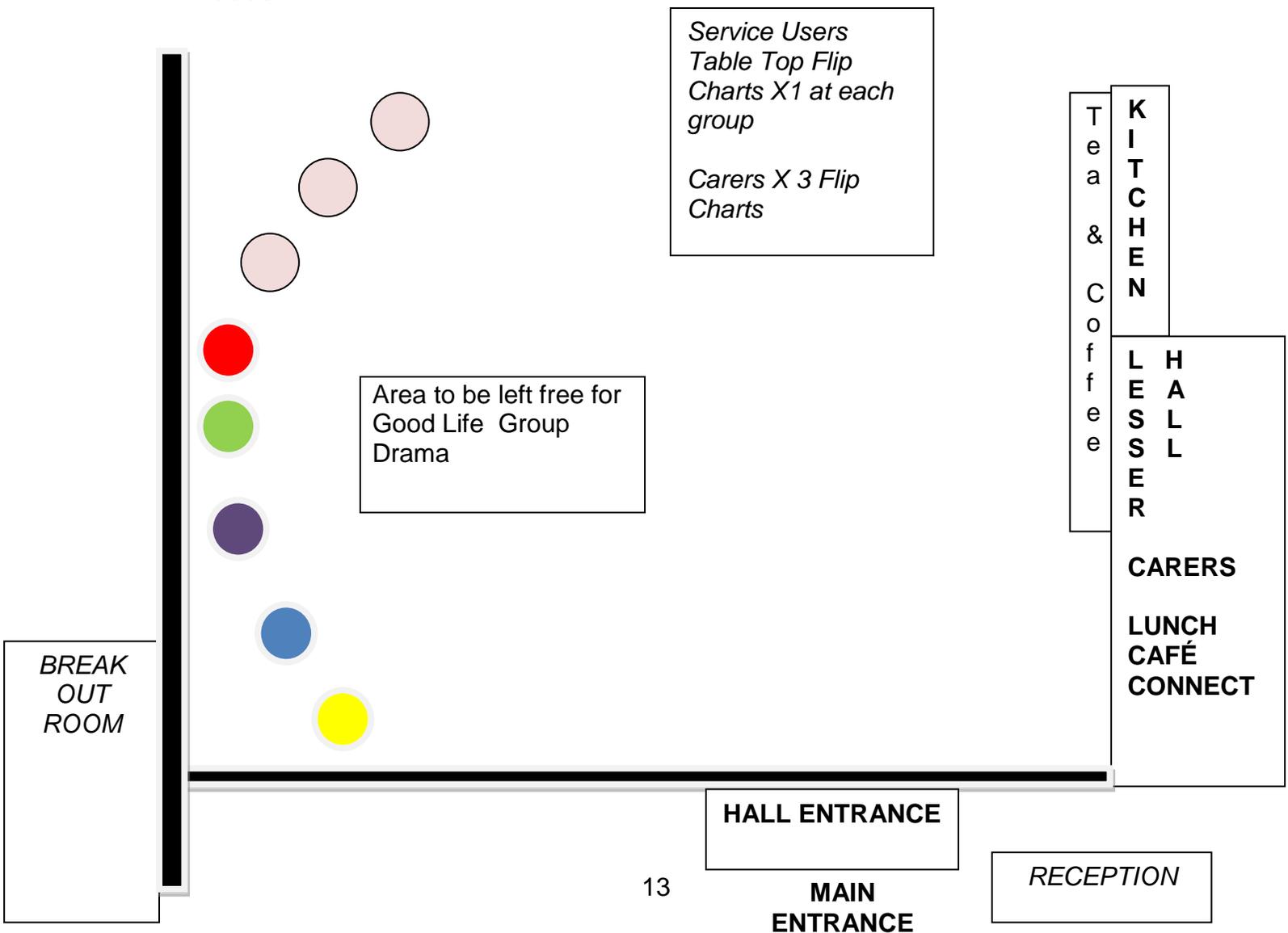
Afternoon Session

PROGRAMME

12.30 p.m. – 1.00 p.m.	Registration, tea and Coffee
1.00 p.m. – 1.15 p.m.	Opening Remarks
1.15 p.m. – 2.00 p.m.	Good life Group & Discussion
2.00 p.m. – 2.15 p.m.	Comfort Break
2.15 p.m. – 2.45 p.m.	Good life Group & Discussion
2.45 p.m. – 3.00 p.m.	Closing Remarks

Appendix 7 – Layout of Hall

-  Carers Tables
-  Service User
-  Service User
-  Service User
-  Service User
-  Service User with Additional Communication needs.



Appendix 7 – Description of Good Life Group Scenarios

Consultation Day Planning **Scene Scenarios**

SCENARIO 1 – SWIMMING

Angela has arranged to go swimming with her Support Worker, Alan, but when they meet up Alan tells her he doesn't want to go. He persuades her to go for a coffee with another service user and his support worker instead. Angela doesn't really want to do that, and she's really disappointed about the swimming – especially as this isn't the first time this has happened – but she agrees reluctantly to go. She feels like she's being prevented from doing something she really wants to do.

SCENARIO 2 – PARENTS

Derek is really excited about a new college course he's been told about, and rushes home to tell his parents about it. His parents aren't very keen and tell him it will be difficult for him to do the course because he needs a computer and would have to travel on the bus to college. Derek is upset and disappointed and doesn't feel he's being listened to or taken seriously.

SCENARIO 3 – LDS CANCELLATION

Allan's friends invite him to the pictures with them, but he can't go because he has an important meeting with Maggie from LDS to discuss his support package. It's already been cancelled and he really needs to ask her some questions about it. But at the last minute, Maggie cancels the meeting again. The only time she can offer is the next day, when Allan's supposed to be at college. When Allan turns up the next day, she has to cut the meeting short because something else has come up. Allan feels like no-one's noticed he has a life, too!

Appendix 9 - Results/comments from the discussion

Comments and Feedback from Discussion Groups

Scenario 1

The support worker wanting to change a planned activity

- There have been times when people wanted to do something but others did not allow it (long time ago)
- Didn't deserve it.
- Unfairly treated
- Some parents have a concern
- Some parents see adults with LD as children.
- Parents can worry too much.
- Could ask parents to take her.
- Check if support from someone else is available at another time.
- Someone's support worker was shopping for her girls when out, service user said didn't want to but felt not listened to.
- Carer and service user is a two way process. Both need to be comfortable with what doing.
- If really unhappy would speak to – Social Worker, Advocacy, Mum.
- When swimming health and safety is a big issue/concern.
- We should be in charge.
- If not happy with a worker can go to a boss.
- Could speak to family
- Could speak to Care Manager.
- Could speak to worker.
- Similar situation with coffee.
- Most people haven't experienced this situation.
- It is not support Worker's time it is Clients time.
- Angela was happy to go swimming.
- Angel was sad when she couldn't go swimming.
- Could not go hill walking – told to high, made me feel upset.
- Would talk to Kate or John.
- Made to go into water – felt scared, once I did it I was happy.
- If unhappy would tell care worker and boss.
- Wanted to go swimming – staff said it was unsafe – would know who to complain to.
- Couldn't go to Glasgow- but just because I didn't know how to do it. Support Worker's helped.
- Would feel sad/upset
- Should be able to go to things I want.
- It all felt very positive about support.

- Would tell Social Worker / Nurse/ friends.
- Negotiate with workers.
- Like people to listen.
- Red table had no problems with their support and doing what they want.
- Support worker has no problems when providing support.
- If support worker said no speak to physiotherapist or manager of service.
- People to listen and respect us.

Scenario 2

Service user wanting to go to College / wanting to do something new.

- Carers worry – say no
- Mum tells me I am not allowed to do things – just ignore her.
- I don't like people bossing me about.
- I feel annoyed and disappointed when I can't do the things I want.
- I feel upset when I can't get what I want.
- Spoke with mum about it.
- Some people don't know what an Advocate does (other helped explain this).
- When trying to get help, nobody helped.
- Protection is better in some places than others (staff who understand make a big difference).
- Get better choices in some places.
- Spoke with person in charge.
- Felt that I hadn't been listened to by parents.
- Speak with Manager – some people might not know who manager is.
- Speak with family.
- Sometimes didn't see manager for a while.
- Can be confusing knowing what manager to speak to.
- Speak to my Social Worker.
- Trying something new needs forward planning.
- Carer needs to be confident that support worker has skills and ability to support well.
- Experience of College not good: Didn't fit in, was too big, people stared at me even when I was there with support worker would not go back.
- If mum worried about me trying something new she can talk to my LD Nurse.
- Timing is a big issue when trying something new, only have 4 hours support, difficult to plan and support worker needs to be on time.
- I can talk to my mum if she is worried.
- We feel happy asking lots of different people for help.
- Parents did not want me to go to pictures. Also brothers and sisters like going to pictures, feel good.
- Other people stop me doing things because of my disability, legal?

- Not my parents.
- Done visit to tall ships, sailing, gliding, spent all my money!! People think I cannot do things because of my disability – proved I can do these things.
- Not allowed to do things – shouted at. Feel like a baby.
- Never stopped doing things – feel supported.
- Sometime feel parents are overprotective.
- Not allowed to go to Glasgow myself because of danger but I know what to do if I get lost.
- Bus to Glasgow, felt sick – taken off bus – supported by workers.
- I spoke to my mum and dad.
- I feel that I could talk to my Social Worker.
- Carer – Time needed. Things don't happen overnight. Parent needs to work out a solution. Chance to get your head around it. Big step. Got get used to the idea. Need to do a lot of problem solving in respect of transport.
- Parents are generally over protective.
- Felt small, uncomfortable.
- Worried about women being alone, more scared to let them travel.
- Must be allowed to try, if fails, well at least you tried.
- Talk to social worker / support worker.
- What is “normal” – let people be supported by friends, disability should not hold them back.
- Be supported to take a chance.
- Wanted to try archery and was told no – due to safety – too much money.
- Feeling – not bothered thought the reason was good – alright – not safe.
- Not allowed to go to Glasgow, mum felt unsafe – bad experience.
- What to do – meet to discuss the risk – such as meet the instructor.
- Find somewhere cheaper.
- Going into Glasgow – make a plan – time of day-when and how to keep yourself safe.
- No problems – If told could not use plot any more.
- Would talk to other members and the one in charge to find out why.
- Cancelled last minute – Boss cancelled it.
- Feels annoyed can't go out – it does happen but accepts it.
- Important to talk to each other and listen to support worker and friends.
- Not allowed to go out at night – make a plan-phone support worker before and after being out at night: - Bell or alarm, mobile, alert and aware of surrounding, using safety equipment, community alarm.
- Not allowed to weight bear – has to use a hoist for safety – doesn't understand why – hasn't been explained.

Scenario 3

Social worker or other professionals cancelling appointments.

- Felt cut – because worker felt it might be seen as abuse.
- Important to have a good relationship with staff.
- Situation resulted in person feeling ill
- Felt very unhappy.
- Wanted to avoid arguments – sometimes it is better to keep peace.
- My Social Worker is always on time, it is okay if he has to cancel.
- If Social Worker communicates well and has a good relationship changing appointments not such an issue- there is an understanding.
- Cancelled appointments make me feel angry, upset, disappointed.
- Expect to be treated with respect and told of changes a.s.a.p.
- If there are persistent cancelations then would inform management to address this.
- Social Worker needs to take time to ensure the arrangement will work and involve all relevant people especially family.
- Could organise for meetings to stop be cancelled.
- Speak with Advocate.
- Should be more social work assistance.
- People recognise time pressures.
- Some people could make another appointment.
- Could say that I cannot put up with this any longer.
- Could ask for another worker.
- I would speak up if I was not happy
- I would speak up for my friend.
- We talked about who we would ask for help.
- We think the SUN Group would help.
- Worker knew they would be off – could have arranged for another staff member to fill in. Felt annoyed, let down, could have been handled better.
- Worker didn't have time for me – makes me feel down. Would say to social worker face to face.
- One time had to wait a day to get someone.
- No cancellations, key worker deals with things.
- Cancellation once. Would speak to Kate or Key Worker.
- Could not get a hold of social worker, do not get a phone call. Standard!! Did get resolved eventually.
- Take too long to reply to e-mail.
- Over looked.
- Sometimes feel okay, but discrimination make me feel worse as I am trying to progress and they are holding me back.
- He should have gone to the pictures.
- Felt disappointed, upset when cancelled, get fed up.
- Felt as though others were more important.
- Want it explained why cancelled.

- Would tell Adrian.
- A good relationship with social worker helps as I will tell her straight.
- It has happened to me – felt upset, felt sad.
- Sometimes okay but can feel sad.
- Need to talk if someone keeps cancelling.
- Communications important.
- Professional go to visit and service user not there – out.

Comments & Feedback from Frieze

Scenario 1: Supporter wanting to change a planned activity:

- My support worker let me down on Monday – we spoke and changed my plans to the next day when they could support me
- I feel annoyed when my support worker says I can't do something
- I do get let down now and again; but what can you do.....you need to deal with it
- **Some non-verbal clients used Talking Mats to show how they would feel (2 sad and 1 happy), they used gestures and facial expressions to indicate the following.....support workers need to know the signs or body language we use to know how we feel about being let down, or wanting to try something
- **One non-verbal man showed that he relies on his friend who can often get a message across better than he feels he can. This same man signed that he feels he would have to agree to changes made by workers or social workers
- **Another non-verbal man was supported to respond that he would go to a particular person in his service (non support staff member) and get them to help him tell 'a boss' that something was wrong or he isn't happy about something or someone – and that he hoped it would be sorted for the next time
- **A non-verbal group of 3 people suggested some people that they would go to (or have gone to) for help to speak up about how they feel: Friends, SUN Group, A man one of them knows and trusts to listen to him and to help him to get his message across to somebody that can do something about it
- Maybe it would be swimming or cooking or something else in a Support Plan and if the support worker can't swim or can't cook; maybe they could join a class together to learn
- I can tell my worker
- The worker should go to her boss if she's not happy
- Staff should reorganise support with other staff if they can't provide the planned support that day
- I've not had any problems with the support – I choose
- I would tell the boss if I wasn't happy
- I would say to the physio if my support stopped me/wouldn't support me to go swimming
- It happened to me once – I ended up doing something I thought I didn't like BUT I found out I did like doing it – and I still do it

- (5 comments) I don't think you should keep disappointment like this to yourself, you should tell a friend, an Advocate, Mum/Parent, the Service Manager, someone you trust
- I think the worker has rights, and there might be a good reason they can't provide a certain type of support BUT it's important to find out what can be done to keep the service user happy
- All Care Plans should reflect changes, and they should be supported-That's why it's important to match people up well with the staff working with them
- Maybe parents or family could help out and take you swimming another time
- Ask what support is available at the times you want to go for a swim
- Some people already feel they can speak to their support worker if this kind of problem arises
- It doesn't matter what you're doing – it's important to have good relationships with the people that support you
- It's not the Support Worker's time!
- You might not know who the manager is
- Sometimes a worker can be 'subtle' about doing or not doing things to get the service user onside (not always on purpose-sometimes people exert influence without fully realising it)
- IMPORTANT - Good communication – not all clients can communicate in an approachable manner
- Families need to know the person is safe and happy
- Sometimes what I want to do just can't happen if it costs too much money
- I've never been in that position
- There's not much point just feeling annoyed – tell the manager because they can do something about it and sort it out
- You sometimes have to remind people it's my time and I have a choice
- It's not always fair on the supporter either; we have to think about health and safety all the time and it's not fair or right when it stops me doing things

Scenario 2: Service User wanting to go to college/do something new

- Social worker could go to the college or arrange a home visit
- Make sure there is a consistency of service
- Speak with an Advocate
- I'm not allowed to go to Glasgow by myself, but I travel to Partick on my own
- I feel I'm not allowed by my parents; they think I'm not safe
- Transition from school to adult life needs to be more simple
- Mainstream schools could take more responsibility
- Good communication is important
- Parents need support too!
- People need to know where to go for info and help
- Sometimes the things I would like to do costs too much money
- Meet with people from college

- Try the bus journey a couple of times with support or family to see how it goes
- Find out who else is going to college, or you might know someone else who is doing the course – buddy up
- Parents might need support and confidence to help their son/daughter achieve or try new things; and they will only have confidence if it happens in a safe planned way
- It was me that decided not to follow up a course. I went to the college – it's too big, I was scared about getting called names. I changed my mind
- (2 service users) Get my Befriender, Social Worker, Advocate, Support Worker to talk it through with the family/carer and the service user
- **For people who can't communicate you have to look, listen, think about body language, and try to get to the bottom of what it is they might want; then take it to someone who can do something for the person to try to achieve what it is they want
- My Mum says no sometimes, or tells me I can't – but it goes in one ear and out the other. I did what I wanted and I was safe
- Sometimes it's not just the independent travel that's a worry. Carers worry about weather conditions, getting soaked, sitting waiting for a bus – there's lots of factors to consider
- If it fails it fails – I'll have tried
- Make plans to be safe
- I need to learn for myself
- It made me feel small
- I would talk to my Social Worker
- I couldn't go to Glasgow so SW helped me
- Sometimes there's nobody to wave a magic wand and make things work out or happen

Scenario 3: Social worker or other professionals cancelling appointments

- If someone cancels I feel disappointed, angry and upset but also sometimes I find it easy to understand if it's been explained why they have to cancel
- This also affects family if they plan for meetings and have to take time off work or change their plans
- Not just cancellations – social work or support staff should phone in plenty time if they are running late
- Everyone can be late – it's just life
- I'm late sometimes too – we are only human
- Social work stuff can sometimes be sorted by a phone call – and doesn't need hours of everybody's time
- **(Non-verbal man) Didn't think he could do anything about it –He doesn't challenge and intimated that he just has to go places when people can fit him in. (Shrugged shoulders).....That's just how it is

- Sometimes the paid person would be glad if somebody else pointed it out to their bosses or managers that there's a time problem
- I think Social Workers are getting better now; I think younger ones are better trained and work better with me now
- I'm a social worker and I know we get pushed at times – it's not good for anyone
- I never went to a lunch with my group one day because I had a meeting with one of the health team; the professional said she was sorry I had missed the lunch, and said she would have changed our arrangement if she'd known. I've to tell her if this comes up again
- It's happened to me, I had to wait a whole day to see someone
- (4 responses) When that happens to me I feel:
Angry Disappointed, Have a bad feeling, Annoyed
- There's nothing worse than "I'll call you back – and it doesn't happen"
- Who thinks life (my life) should stop to suit somebody else's job or timetable – not me
- Broken promises are rubbish!
- Why can't the social worker put her client first? Is that not her job?
- Be more assertive
- Get someone with more time to work with/meet with the service user
- *(2 clients with limited communication) If I was Alan I'd say 'yes' too – I think I have to agree
- Maybe SWD is overworked or under pressure – but that's not my problem, but it feels like it sometimes
- Nobody's perfect, life's not perfect – but when there's problems or just something planned that has to change, I need to know where I am and that I can depend on my social worker or support worker

Other Comments & Notes:

- (Carer) Carers also have a life of 'fixed support', we always try to arrange things to keep our daughter happy – but the reality is – nobody's happy
- (Carer) Parents and carers have limited say in services/support. Sometimes it's us that seem to always say 'no'- I don't feel I have a choice either – so it might look like it's me that's holding my daughter back- it's not. This is a real family pressure
- (Facilitator) This day wasn't right for everyone- 2 non-verbal service users left early, and another man left a bit later – however it was their choice and staff supported them to exercise that
- This was quite good – I'm putting some of the stuff in my PCP for staff to help me with
- (Carer) I think that some people who live on their own sometimes struggle when meeting SW or "paid people" – they might need more support
- (Carer) This is good – the dramas are very good

- 2 service users – I'd love to go swimming but there's not good access to swimming and hydrotherapy locally – can LDS not make sure this is pushed for when the new pool opens in Clydebank?
- (WDC Staff) I'd like to see people with complex needs or communication difficulties having an Apple iPad to help them make choices and speak for themselves.