



## Swindon

# Learning Disability Partnership Board

## Forum



“What does good support  
look like?”



15<sup>th</sup> November

Pilgrim Centre - Swindon

9:30 – 12.30



## Learning Disability Partnership Board

### Attendees

Name	Organisation
Mary Anne	Saracen Care
Hayley Dolby	Saracen Care
Julia Everard	Saracen Care
Mariama Ibrahima	Saracen Care
Mark Edwards	Healthwatch Swindon
Pam Forde	Healthwatch Swindon
Rachel Hill	Swindon Advocacy Movement (SAM)
Paul	Open Door
Annie Baker	SAM
Rachel Grabowski	SAM
Richard Pike	SAM
Tammy Peapell	LDBP Rep (SAM)
Delyth Brown	SAM
Kelly Moss	LDPB Rep
Teresa Hardman	LDPB Rep (SAM)
Lynnette Glass	NHS Swindon Clinical Commissioning Group (CCG)
Sadie O'Reilly	Open Door Centre
David	Open Door Centre
Suzie Simpkins	LDPB Carer Rep
Jo Chandler	First City Nurses Provider Rep
Sarah Crabb	Open Door
John Reyes	Swindon Circle / Open Door
Steve Morgan	White Horse Care Trust (WHCT)
Dan Eldridge	LDPB Assistant Chair
Sheila Hale	Carer
Susanna Jones	Swindon Carers Centre
Luke Bull	Saracen Care
Stephan Frost	MENCAP
Mary Herowych	MENCAP
Lizz B	MENCAP
Francis Lewis	MENCAP
Sheila Exton	MENCAP
Lucy Beasley	WHCT
Ellen Ferguson	WHCT
Lucy Gibson	SAM
Kay Reeve	Swindon Borough Council (SBC)
Cath Johnston	SBC
Elaine Turner	SBC
Apologies	
Wendy Johnson	Great Western Hospital (GWH)
Dawn Dixon	SAM
Marty Slade	WHCT
Graeme O'Malley	NHS Swindon CCG
Ray Ballman	LDPB Chair



## Learning Disability Partnership Board

### Welcome

Cath welcomed everybody to the LDPB forum.

The topic of this forum was 'What does good support look like?' As well as adults with learning disabilities and carers, we invited all of the organisations and agencies who provide the range support on offer in Swindon. We also invited professionals from the SBC and Swindon CCG.

We offered separate tables for people with learning disabilities and people who support them and asked people to speak openly without inhibitions. We had advocates and volunteers facilitating the discussions and recording what was said.

### Introduction

Kay Reeve (SBC) gave an introduction to the forum. The purpose of the forum was to hear from lots of people in the learning disability community, especially adults with a learning disability and those giving the support.

She spoke about the different supporters we have in our lives - social workers; carers; Personal Assistants; anybody who provides us with support.

It was very important for people to be open and honest, as this would enable us to really learn from the forum. As it was a forum, we couldn't talk about individual cases, but there was a space for table facilitators to note these down so they could be looked at after the forum.

Everybody's voice was important to get a complete picture of what good support looks like.

### Ice Breaker

To help people at the forum to start talking about support Kay introduced an Ice Breaker. Everybody was given a 'one page profile' to complete with others on their table. This is a tool used to get a snap shot of someone's life and is often used in support planning.

We asked people at the forum to let us know what they thought about the exercise. The comments have been put into three groups.

#### 1. What's important;

- It's good to share what you like, e.g. Walking, if it's taken notice of
- It's important that people who support me know about ME!



## Learning Disability Partnership Board

- It's important to hear my dreams

### 2. Not so good;

- Done loads of one page profiles, no-one asks if I've done one before/who with, if they are useful, if I want to do another one
- Thinking about dreams and goals can be hard – people may need support for this
- It's difficult to share if you don't know the staff and they keep changing. Important to have the same support worker although this is challenging to achieve

### 3. Communication;

- How can we do this with people who have limited communication?
- Must respect the knowledge of the individual and find out about them from them by all means available
- Also the knowledge of others
- Observe more and watch for indicators of needs, wants, desires – likes/dislikes

## Activity 1 – Care and Support Planning Quiz

Each table was given a true or false quiz about care plans.

People worked in small groups to discuss the answers. The idea of the quiz was to get people thinking more about care plans. The learning disability community often talks about care plans. We wanted to give people the opportunity to think about them in more depth.

The questions in the quiz are below. Have a go and find the answers on the last page of this report.

- |   |              |
|---|--------------|
| 1. I know what a care plan is                                     | TRUE / FALSE |
| 2. I must be involved in writing my own care plan if I want to be | TRUE / FALSE |
| 3. My care plan is only about the services I need                 | TRUE / FALSE |
| 4. I should be given choice and control over how my needs are met | TRUE / FALSE |
| 5. People don't have to take notice of my care plan               | TRUE / FALSE |



## Learning Disability Partnership Board

- |   |              |
|---|--------------|
| 6. If I need support to do my care plan I can choose who helps me | TRUE / FALSE |
| 7. I should have a copy of my care plan if I want it              | TRUE / FALSE |
| 8. I need to agree about what's in my care plan before I sign it  | TRUE / FALSE |
| 9. My care plan review doesn't need to include me                 | TRUE / FALSE |
| 10. I can't ask for a review of my care plan                      | TRUE / FALSE |

We asked the forum to give us some feedback about the activity. We wanted to know if there were any answers they were surprised by and how they felt about the care plan process in general. This is what people said;

### 1. General comments;

It is *their story*

The care plan is really important to me.

People do need to take notice of our care plans.

Not everyone wanted a copy of their care plan.

I don't like sharing it [careplan].

Time to communicate is important.

If you are able enough to make the choices you should be able to.

We all need choice in life – all the time.

Not everyone felt they had enough choice.

I don't agree that the care plan should only be about the services you are using, because I should be given more choice.

We should have a regular review. They [staff] haven't got a clue.

I should have a say - I might not want to do something or be able to do something but I'm not asked.

### 2. General Questions;

What is the difference between an assessment and a plan?

Is the care plan for the cared for or carer?



## Learning Disability Partnership Board

Do carers have care plans?

How does the care plan get signed off?

A care plan means different things to different people – care plan, support plan, blue book, HAP etc. How do we know the links between these documents across organisations?

What happens if it's lost?

### **3. More Specific Comments, Questions and Potential solutions**

Please see the table on the next page. The table notes comments that people made whilst discussing the quiz questions. It identifies potential solutions to the issues raised.

**Please note that there are specific actions for specific people to follow.**



## Learning Disability Partnership Board

Topic	Comments	Who should think about this?
The care plan / reviews	Choices are often restricted or even removed due to lack of funding or allocation of social worker. If level of support is limited some needs/desires are not put in the care plan.	<p><b>Who:</b> Providers  <b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB.</p> <p><b>Who:</b> Social Workers and Commissioners  <b>Action:</b> Discuss at Adult Social Care (ASC) Team meeting. Feedback to LDPB.</p>
	Changes in circumstances may potentially require funding conversations for additional support needs. If this happens before an annual review is due it can be challenging to move it to an earlier date due to social work resources. However, a timescale of 3-6 months for the review to take place is not helpful.	<p><b>Who:</b> Providers  <b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB.</p> <p><b>Who:</b> Social Workers and Commissioners  <b>Action:</b> Discuss this as the LD Provider Forum and ASC Team Meeting.  Also the LD Duty Team can be used as a resource to support a request for a review</p>
	The assessment of 'urgent' can differ from an individual, provider and adult social care. How can we work together to have a clearer understanding between each other about this?	<p><b>Who:</b> Providers  <b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB.</p> <p><b>Who:</b> Social Workers  <b>Action:</b> Discuss at ASC Team meeting, then feedback to LDPB.</p>
	How are plans shared and not duplicated?	<p><b>Who:</b> Providers and Social Workers  <b>Action:</b> Be in regular contact with each other to ensure there is only one plan which is owned by the service user.</p>
	Person needs a copy of the plan and be told who else has a copy and where it is kept safely.	<p><b>Who:</b> Providers and Social Workers <b>Action:</b> Ensure that all their service users have a copy of their care plan.</p> <p><b>Who:</b> Contract Managers  <b>Action:</b> Could this be assessed at contract reviews?</p>



## Learning Disability Partnership Board

Topic	Comments	Who should think about this?
The care plan / reviews	The care plan should reflect the changing lives of people. It should be a living document, current, dynamic. It must be used to show changing needs e.g. medication, needs for physical support/hoist, increased care needs etc.	<p><b>Who:</b> Providers</p> <p><b>Action:</b> At LD Providers Forum consider how providers can take responsibility for having regular contact with service users and use the care plan regularly to look at progress and not just looked at it once a year. For example have tenants meetings to discuss general issues about care plans and reviews.</p> <p><b>Who:</b> Social Workers</p> <p><b>Action:</b> At the ASC team meeting discuss how the care plan can be a living current and dynamic document.</p>
	If the person lives more independently they may need help to know how it can be updated.	<p><b>Who:</b> Providers</p> <p><b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB</p> <p><b>Who:</b> Social Workers and Commissioners</p> <p><b>Action:</b> Discuss at ASC Team meeting, then feedback to LDPB.</p> <p><b>Who:</b> Adults with LD</p> <p><b>Action:</b> Ask support worker.</p>
	If I asked for a copy of mine it would take forever.	<p><b>Who:</b> Providers</p> <p><b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB.</p> <p><b>Who:</b> Social Workers and Commissioners</p> <p><b>Action:</b> Discuss at ASC Team meeting, then feedback to LDPB.</p>



## Learning Disability Partnership Board

Topic	Comments	Who should think about this?
<b>The care plan / reviews</b>	It is important when a care plan is first drafted that people are informed that they can request a review and who might help them with this.	<b>Who:</b> Providers and Social Workers <b>Action:</b> Always tell service user and consider who might be able to help now that there is no LD advocacy anymore.
	Supporters need to understand an individual's care plan.	<b>Who:</b> Providers <b>Action:</b> Providers to consider these solutions put forward at the forum; "Have a group of 'bank staff', not agency staff, who are known to the residents and use regularly to cover other staff. This means that trust can be built with residents".  "Whilst it's preferable to have consistent staff <b>and</b> support, if staff do need to be changed, <b>knowing ahead of time really helps</b> ".

Topic	Comments	Who should think about this?
<b>Staff / Support workers</b>	Staff shouldn't share they're issues with high caseloads and not enough time to support you.	<b>Who:</b> Providers <b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB. <b>Who:</b> Social Workers and Commissioners <b>Action:</b> Discuss at ASC Team meeting, then feedback to LDPB.
	Social workers / support workers say they will do something and they don't.	<b>Who:</b> Providers <b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB. <b>Who:</b> Social Workers <b>Action:</b> Discuss at ASC Team meeting, then Feedback to LDPB.
	It's not helpful when they keep looking at their watch – makes you feel they don't have time for you.	<b>Who:</b> Providers <b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB. <b>Who:</b> Social Workers and Commissioners <b>Action:</b> Discuss at ASC Team meeting, then feedback to LDPB.



## Learning Disability Partnership Board

Topic	Comments	Who should think about this?
Communication	Adults with LD don't always feel confident to say when they're not happy with their support, how do we increase their confidence?	<p><b>Who:</b> Providers and Social Workers</p> <p><b>Action:</b> Consider the following solutions from forum;            "Ask more questions to show it's ok to say things aren't ok."</p> <p>"Mutual trust is very important- don't manipulate – record exactly what is said – don't take things personally – always clear the air."</p> <p>"Develop some simple confidence building activities with adults with LD."</p> <p>"More opportunities like the LDPB Forum for adults with LD to understand their rights and build their confidence."</p>
	How do we involve adults who are unable to communicate verbally and support them to take ownership?	<p><b>Who:</b> Providers and Social Workers</p> <p><b>Action:</b> Consider solutions put forward at Forum;            "Staff need to be able to use different communication methods – sign language, pictures, eye contact etc."</p> <p>"If appropriate, ensure whole network around the adult are involved to share their knowledge – even those who don't live near".</p> <p>"Could we share good practice between Providers – do we need some training for support workers?"</p> <p>"Don't use complicated words or jargon".</p>



## Learning Disability Partnership Board

Topic	Comments	Who should think about this?
<b>What can we do when people don't agree about their care plan?</b>	Not everyone agrees to their care plan so don't always sign it.	<b>Who:</b> Providers <b>Action:</b> Discuss this at the LD Provider Forum, then feedback to LDPB.
	Sometimes they don't ask you they just get you to sign it.	<b>Who:</b> Social Workers and Commissioners <b>Action:</b> Discuss at ASC Team meeting, then feedback to LDPB.
		<b>Who:</b> Providers and Social Workers <b>Action:</b> Consider solutions from Forum; "Relationships with key workers/support workers is crucial to building trust – regular meetings can help this – reminders about how complaints can be made."  "Clarify what the difference of opinion is about – level of support/type of support/activities desired/how support is delivered. This will help decide who needs to be in the conversation about resolution e.g. if funding/level of support this probably needs to go back to the social work team; if about how the support is delivered/types of activities this may be a conversation with the Provider."



## Learning Disability Partnership Board

### Other potential solutions

- Could we develop a Frequently Asked Questions (FAQ) leaflet based on the quiz questions and feedback? Would this be helpful?

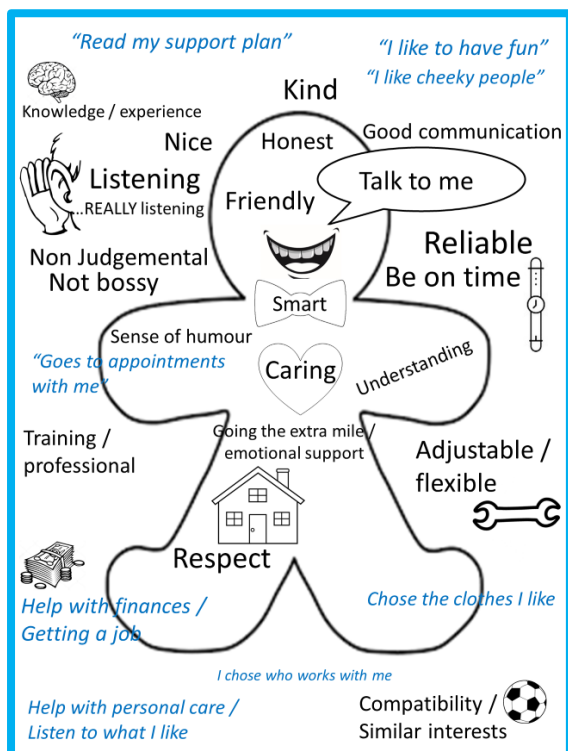
**Action:** Cath to take to LDPB

### Activity 2 – What does a good supporter look like?

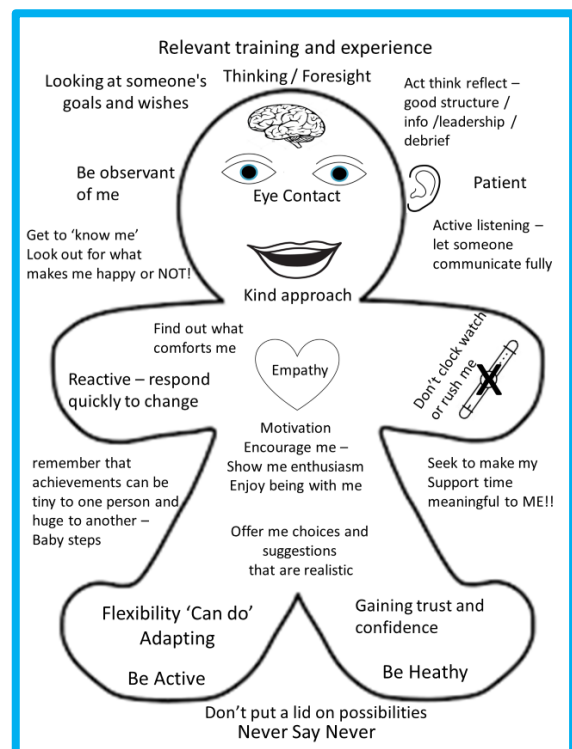
In this activity we asked each table to draw an outline of a person. We wanted people to think about the qualities of a good supporter; what makes them 'good'? People could do this in picture form or write words.

*Below shows what everybody said;*

This is what the adults with learning disabilities wanted from a supporter



This is what carers and support workers wanted in a supporter





## Learning Disability Partnership Board

This is what another group of support workers said was important in a supporter:

**Good listener**   **Friendly**   **Approachable**   **Empathise**  
**Caring**   **Flexible**   **Knowledgeable**  
**Empowerment of person being supported**   **Confident**  
**Competent**   **Communication**   **Team Work**   **Not Judgemental**  
**Good sense of humour**   **Risk Management**   **Professional**  
**Boundaries**   **Positive Outcomes**   **Honest**   **Trust (Build Trust)**

**Action:** Providers could think about this information when recruiting new staff. Commissioners could think about this information when tendering new contracts.

### Activity 3 – Scenarios and solutions

Due to so much discussion and excellent feedback from the first two activities we ran out of time to complete this exercise.

This activity was going to look at different issues that can effect good support, such as support staff shift changes, taking risks and access to money.

We still feel this would be a great activity to do and think we would get some really good feedback from the groups. Cath will contact the various people who attended the forum to organise how to complete this activity.

### Summary, pledges, next actions

Kay thanked everybody for coming along, and for joining in with the discussions. Without people coming to the forum and telling us about their experiences, it would be impossible to make any changes.

To keep people engaged and thinking about 'good support' we asked everybody to fill in a pledge sheet. This asked them; "To help make support more person centred I will....."



## **Learning Disability Partnership Board**

These pledges were for everybody, support workers, carers, people receiving support, and facilitators. Lots of people took these pledges home, to make sure they remember them. Some of the pledges people made were;

“Be very clear about what I really need from my support worker.”

“I want a new care plan if allowed.”

“Continue to communicate with my service users and discuss changes that they want to put in their care plans.”

“Listen more.”

“Talk more about my needs”

“Have more meetings with the person I support when on shift.”

## **Next Actions**

- Cath Johnston to take suggestions about FAQ leaflet to LDPB.
- Marty Slade, Jo Chandler and Cath Johnston to take actions for Providers to LD Provider Forum.
- Cath Johnston to take actions for Social Workers and Commissioners to Adult Social Care team meeting.
- Annie to create a Newsletter from the report.
- Annie to circulate report and newsletter to all networks.
- Cath to contact organisations who attended the forum to set up the ‘scenario activity’.

## **Evaluation**

To make sure the forum is run in a way that people are able to engage in, we asked people to give us feedback. This might be to tell us they have enjoyed it, or what we could do differently to improve it.

Last time we were asked to use a microphone and to change the set-up of the room around so that the projector screen could be seen more clearly.

We asked the Pilgrim Centre to provide us with a microphone, they were able to do this but unfortunately it wasn’t a cordless one. To make sure everybody was heard, Kay repeated any questions or comments made by people over the microphone.



## Learning Disability Partnership Board

We did ask that the room be set up in a way that would make it easier to see the projector which was confirmed over the phone. Unfortunately this request had been missed and the projector was still in a difficult position. This is something that we will feedback to the Pilgrim Centre.

The feedback from this forum included:

“Very good, informative and fun.”

“Really positive, very empowering for the adults with LD. Everyone wanted to participate”

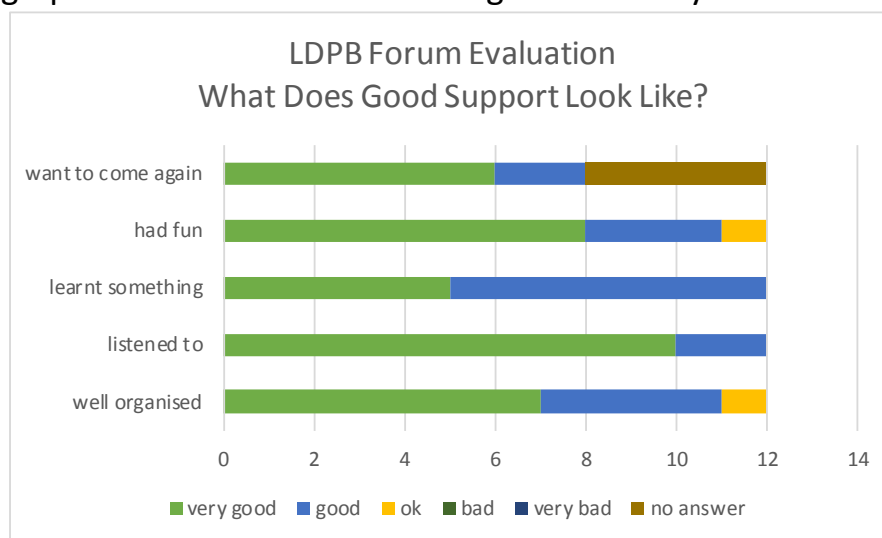
“Good workshop, enjoyed and learnt a lot.”

“Everyone had opportunity to put forward their views, everyone around the table listened”

“Very noisy tables; good energy in the room (ground rules may help?)”

“Keep track of time”

Here is a graph to show the feedback we got on the day:



## Swindon LDPB Logo

The Board had decided to come up with a logo to help give the Board an identity. The LDPB Learning Disability reps came up with a shortlist of 3 designs for the logo. They visited different places including OK4U's People's Group and Open Door to get as many people to vote on their favourite logo as possible. They also asked people at the Forum to vote.

Over 40 people voted on the three shortlisted logos.



## Learning Disability Partnership Board

The winning logo is



## Learning Disability Partnership Board

### Individual Stories

We received some personal stories about what works well when being supported:

1. An individual who wanted to move back to Swindon to be closer to family and friends.

**Enabled** by support workers to visit Swindon.

**Included** in interviewing potential new support workers.

**Empowered** to identify the people he wanted to support him, "I like to be treated with respect".

2. "I am lucky that I have a good care company, who **treat me with respect**. Because they are **a good company they hang on to their staff** and I have had the **same carer for 3 years** who **knows me** like the back of his hand. It is **very important to me that I understand which staff are coming in which day**.

I drive the process and my own care plan, because **I know what my needs are better than someone sat in an office** or who has never met me."

### Additional resources

Please find attached with the accompanying e-mail of this forum write up:

1. An example of a 'One Page Profile'
2. 'Think Local Act Personal' support planning guidelines from the Care and Support Planning Guide.
3. "Supporting Me" A guide for Personal Assistants employed by or for someone with a learning disability.

### Answers for quiz

1. - 2. True 3. False 4. True 5. True 6. True 7. True 8. True 9. False 10. False