

CAMHS

Participation Training

By

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Aim:

To work towards ensuring that participation of users and carers is embedded within the Child and Adolescent Mental Health Services that you provide.

How can we do this?

By looking at:

- Where you are now?
- Where do you want to be?
- How are you going to get there?

Ideas Avalanche

- What is Participation?
- What does it mean?
- What does it look like?
- When can it happen?
- Where can it happen?

What is Participation?

Definitions that will be used within this service:

There is much confusion about participation and the language that is used to describe it such as involvement and consultation. This confusion is evident within the CAMHS teams and therefore we feel it is vital to clarify the meaning of participation in regards to our service.

We intend to use the adapted model on the next page when talking about participation within CAMHS. The model is flexible enough to enable good participation to occur without making unrealistic demands on the CAMH services. The aim is for services to move above the line, operating within a chosen degree of involvement that is realistic to the activity or objective. To remain below the line would be to operate in a non participatory way.

***Participation** is a dynamic approach that actively involves users and carers in exercising or sharing control in decision making regarding issues that are relevant to their lives such as:*

- *The services people need and the way in which those services are delivered.*
- *The policies adopted by the organisation and*
- *Input in the strategic planning of the future services.*

The participative activity usually is a short term project with an end goal that involves the same young people from beginning to end.

***Involvement** is an intense and ongoing process of how true participation is realised. You have to involve users / carers to achieve participation.*

This can be done through a variety of different degrees and within a variety of different roles. It is flexible and moveable it can start with tokenism and end in shared control or even control. The model we are using below is non- hierarchical as to recognise that in certain areas involvement may never result in young people holding control but rather in shared decision making or consulted and informed.

***Consultation** is a two way process that creates a dialogue between the service and users/carers about the service provision, plan and policies.*

This usually occurs as a one off event within a time frame. For this not to be tokenistic careful thought needs to be given to how users/ carers views will be taken on board and how they will be fed back to.

***Information** is a one way process that informs user/carers about the service, policies or activities.*

To bring about successful participation, involvement or even a consultation exercise you have to provide relevant and transparent information to the users / carers ensuring they can make or share in making an informed choice or decision.

The Law:

Children Act 1989

“The child and young person’s welfare is paramount and safeguarding and promoting it is the priority. Service providers must listen to and work in partnership with children, young people, parents, others with parental responsibility and relevant others.”

“Local authorities have a duty to ascertain the wishes and feelings of a child/young person whenever making a decision concerning a child.”

UNCRC

Article 12 summary: “Children have the right to say what they think should happen, when adults are making the decisions that affect them, and to have their opinions taken into account”

Article 5: “ The rights of the parents/carers and family must be reflected.”

NHS Health Advisory service report, Together We Stand (1995):

“Children, young people and families must all feel that a service has enabled them to present their own perspective on the problems that they bring and that they have been listened to....Such communication is...a potent test of a service’s accessibility.”

Section 11 in the health and social care act 2001

introduces a new duty on the NHS to involve and consult with patients and the public which is reflected in 'The NHS Plan':

'Our vision is to move away from an out dated system of patients being on the outside, towards a new model where the voices of patients, their carers and the public are heard through every level of service....the patient must be at the centre of everything the NHS does.' (The NHS Plan)

The National Service Framework for Mental Health's 10 year plan outlines and represents new ways of working and new child centred models of service delivery. This document culminated through consultation, highlights the importance for services to make sure that they ask users/carers/parents what they want, to listen to what they say and to adapt their services to the needs expressed.

Children Act 2004 highlights 5 standards that are key to the well being of children. These include being healthy, staying safe, enjoying and achieving, making a positive contribution and achieving economic well being.

Every Child Matters: Next Steps, recognises that to improve these outcomes radical change needs to happen in the whole system of Children's Services.

One change is to:

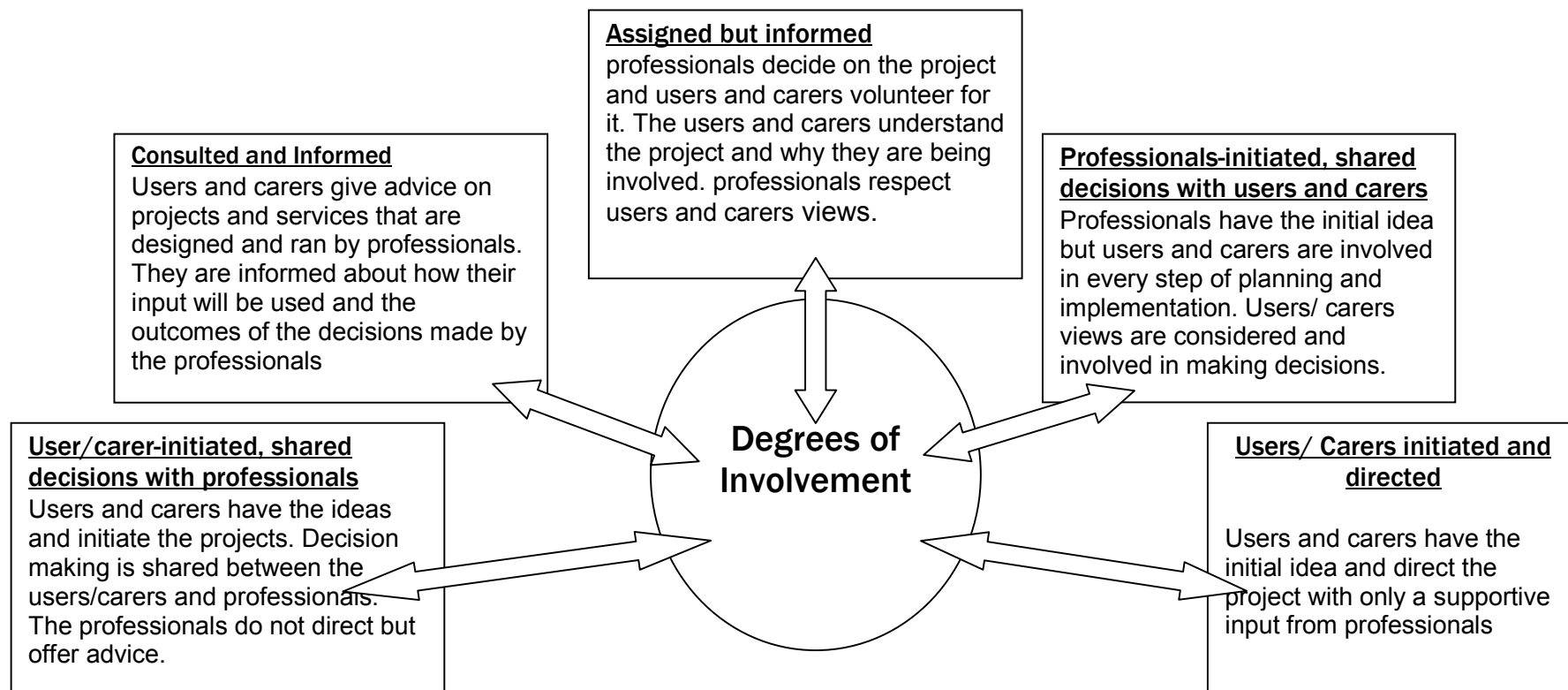
“Listen to children, young people and their families when assessing and planning service provision, as well as in face to face delivery.”

It is the Government's intention that children, young people and their families will have a “strong voice” in the changes ahead.

It is important to :

Ensure participation is not an end in itself but a means to a change (**SCIE 2004**)

participation



non - participation

Benefits of Participation

For services:

- Improved service development – they will be more effective, better targeted and received. This saves money.
- Improved client support
- Increased access and use of services
- Increased participatory practice
- Improved ability to achieve organisational goals such as aiding social inclusion.
- Participation contributes to the success of services
- Enhanced credibility and reputation especially with funders and young people.
- A wider variety of perspectives offered e.g. fresh and new ideas, enthusiasm, innovation and creativity
- Improved organisational processes/systems - added fairness and justice
- Building capacity and sustainability within an organisation
- More success in drawing in marginalized groups
- Users and Carers can make powerful allies in helping to promote change.
- Can help to change public perceptions of mental health.
- Better targeting of resources as service built around need.
- Networking and sharing skills with other agencies.
- Promotion of CAMHS
- Improves decision making.
- Enhances democratic process

For services users/carers:

- Confidence and self-belief
- Practical skills
- Knowledge and education
- Behaviour
- The development of group skills
- The erosion of gender divisions between participating young people
- Increased relevance of services to young people
- Community cohesion is fostered through the inclusion of service users in decision making.
- Raising of aspirations between service users and carers.
- The involvement of young people in their treatment e.g. self administering medication, may lead to greater compliance with their treatment, especially self-harmers and the chronically ill.
- Can contribute to their development as responsible citizens and make them feel valued.
- Participation gives users an active role that can aid their recovery (recovery approach)
- More ownership over their lives and services accessing.
- Given opportunity to play more of a part in defining their health needs.
- Learn to consider the needs and feelings of others and understand compromise.
- A chance to make a difference.
- Useful in a CV for potential employees
- Having fun and meeting new people

Barriers of Participation

Services

- A lack of understanding about what user and carer involvement means.
- Lack of capacity and commitment from service
- Lack of skills to do participation
- Culture of organisation
- The view that professionals know best!
- Participation often becomes tokenistic and a phase of the government. To achieve real participation, time is needed to build up relationships, trust, knowledge of the process and confidence.
- The resistance of staff on ground level not promoting the involvement or giving the service users the knowledge of the opportunities to.– Lianne Picot
- The lack of research evidence around participation that has occurred creates little evidence of its benefits keeping it at a low priority and also creates a sense of fear of the unknown within workers. – Save the Children
- Not enough service users partake in participation due to various reasons:
 - Short term relationships not enabling or developing a sense of trust and commitment towards CAMHS.
 - A sense of wanting to leave this period of their life behind.
 - A lack of confidence as if what they have to say is not worthy or important this can be highlighted by the lack of their understanding of jargon. Make the language of the work and participation more accessible.
- This lack of uptake enables professionals to discredit the research due to the low numbers being unrepresentative. – Sibbicks ‘Dynamic’ research.
- Participation is not given enough resources to enable its sustainability – treated as flavour of the month then forgotten about. It needs to be given commitment from the beginning in regards to accessibility, positive environments and a willingness to take on change.
- Language – the word ‘mental’
- The title – CAMHS not being recognised.

Service users/carers

- Young people and carers may not identify themselves as users of mental health services – stigma attached.
- Fear that services may be withdrawn if comment negatively on them.
- Over consulted with no change
- Public attitudes to mental health - stigma
- Ex-users may not want to revisit past experiences
- Due to past consultation having been random and inconsistent, patients lose motivation and faith to be involved and become cynical about participation and its affect upon services – They become disempowered. Participation needs to be ongoing, sustainable and led by the users/carers to be successful.
- Physical access to events for disabled young people.
- Communication barriers.
- Frustration at lack of feedback
- Participation is still generally through formal processes that are either – boring, scary or intrusive.
- Users not identifying themselves as users of mental health services.

Event Planning - Discuss and plan the process of setting up the given event.

Look at the planning of the event in three ways:

- As Professionals setting up the event
- As Users and Carers setting up the event
- As Professionals working together with Users and Carers to set up the event.

Questions to think about and discuss:

What does the process of each look like?

Where would the process fit on the participation models presented today?

What are the positives and negatives to each process?

Event Planning Scenarios:

Event 1:

Recruitment and selection

Event 2:

Developing promotional material – Service Leaflet

Event 3:

Focus Groups for qualitative research.

Look at the most participative method:

Where does it fit on the CAMHS model of Participation presented today?

Do you do it now?

Could you do it in the future?

Consider its implications to your work?

Would it be useful?

Would there be limitations?

What resources would you need?

How much power/say would users and carers have in prioritising the topic, aim, method, level of involvement?

What activities could users/ carers carry out or work in partnership with?

What support would staff need for its success?

What support would users carers need?

How will measure the success of the method, impact it has had on service?

Event Planning Process

Why do I need to involve users and carers and what do I want to achieve by doing so?

What level of involvement is right for the task? Is it participative – Look at CAMHS Participation model.

Is this duplicating work? Has it been done before?

Are there any partners, other agencies that would be able to assist the work?

When do I involve users and carers – will they help in the planning and design?

How will I access service users and carers?

What specific needs will they have? (Access, interpreters, childcare)

How do I make it as accessible as possible ensuring equality? What time will it be held? After school and work as to not impact on education or employment?

How do I promote the event/ activity? Do I involve users and carers in this?

Should the activity be broadened to capture potential service users or ex service users?

How shall I involve the users / carers? Will the method be chosen by the users and carers?

Timescales to work to?

Do I have enough skills for this or do I need to seek extra training?

Resources (Money, location, capacity.)?

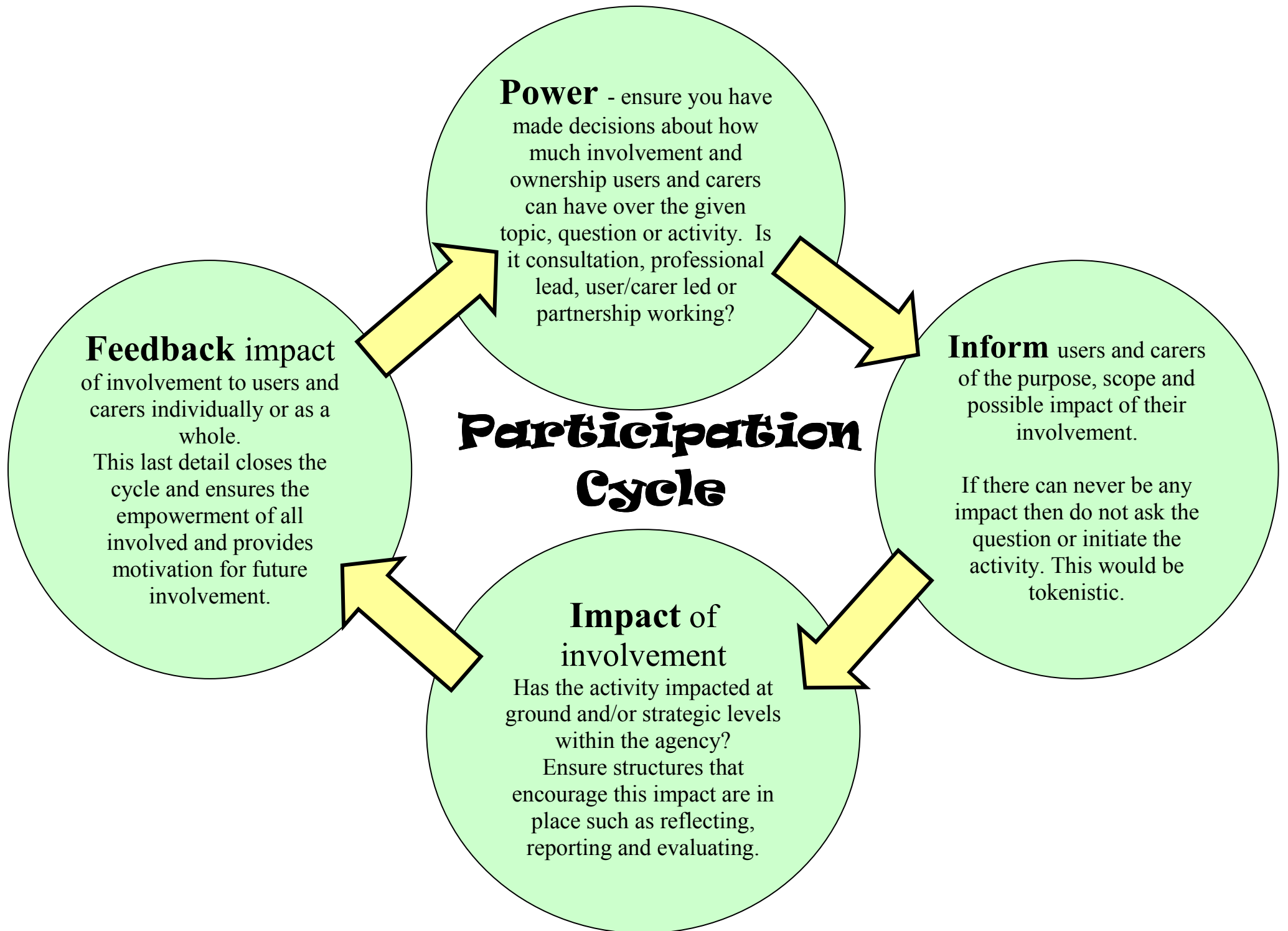
**How will I provide safe and supportive environment for those involved?
Confidentiality, anonymity, opt out plan Ground Rules?**

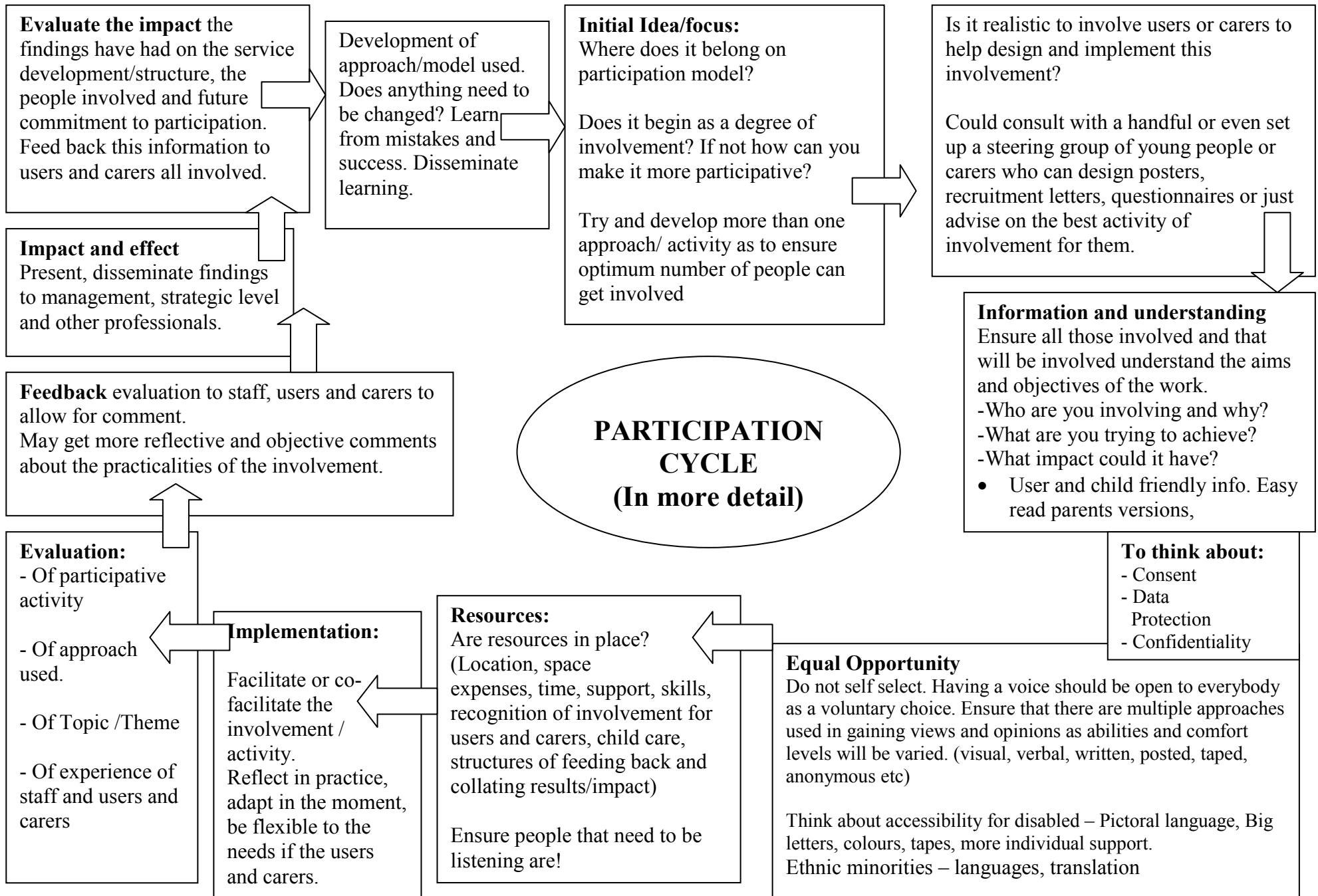
Procedure for dealing with findings, ideas and information that emerge? Who presents findings professionals or user and carers in partnership? Who analyses and interprets findings – partnership again?

How to feedback impact and possible change to those involved?

Evaluate the event – feedback from those involved, affected by it and funders. Was it worthwhile?

(Adapted from Service User and Carer Involvement Toolkit 2001) Nicola Swales 2005





Top Tips for Participation!

Be honest and clear about the purpose, what is required and the possible impact of the participation.

Start small, begin to affect everyday choices and gain practice to affect bigger ones.

Encourage the users and carers to set the questions, the focus of the involvement.

There is no single right method for participation as all users and carers are individuals and different, therefore there should be a choice for them of how and to what extent they get involved.

Provide training for users and carers, enable them to understand their rights and the purpose of participation.

Ensure that the activity is pitched at the right level – informal, flexible, relaxed, unthreatening, understandable, fun, creative, stimulating.

Users and carers need sufficient information in order to enable them to make decisions about participation.

Participation is not an add on it needs to be built into planning cycles as an integral part of meeting peoples needs.

Participation should be equal and accessible to all.

Be clear about the power and responsibilities users and carers can have within the activity.

Good opt out strategies need to be implemented to protect users and carers.

Agreements around anonymity and confidentiality will need to be met.

Do not use Jargon and acronyms. Ensure the language is accessible to all.

Approach other agencies to aid with participation work, this will enable the sharing of skills and promote the image and understanding of CAMHS

Avoid self-selection of candidates if possible as everyone has a right to an opinion and to be heard.

Take time in building relationships, participation does not happen overnight!

Treat the users and carers as equals, give them respect and value their opinions.

Accept that some users and carers will find it harder than others to participate, allocate patience, time and commitment to find appropriate involvement for them.

Always feedback to users and carers the impact of their involvement.

Give users and carers an opportunity to interpret and analyse the data/ findings themselves – feed this into findings.

When an activity, event, group comes to an end consider its sustainability in a different format e.g. a parent support group a youth committee or signposting to similar events/ support

Quotes

Participation:

“Is about getting and sharing information, making a difference to decision making, being treated with respect, and understanding ones rights. Service user participation within mental health context should improve mental health services and move the experience of service users from exclusion to inclusion. Mental Health service users writing and talking about their experiences emphasise that their participation in decision making within services must be available, real and meaningful.”

(Service user participation in mental health services, a discussion document. mental health commission 2002)

Complaints:

Don't let individual complaints obscure the broader issue, but make sure that these are dealt with sensitively and effectively outside the involvement process.

Don't be defensive criticisms and challenging perspectives can be constructive and useful.

(Service user and carer involvement toolkit, Leeds health action zone,2001)

Resistance:

“The burden of proof always rests with those who wish to exclude others from participation; children should not be obliged to argue their case for possessing the same rights as everyone else”

(Franklin, 1995, *The Handbook of Children's Rights*.)

Experts

“Whatever our fears, young people themselves are the ones most likely to know what they like and don't like, and how a problem affects them. So its up to us to listen on all channels.”

(Involving young people in decisions about their lives, AMAZE)

List of possible participation activities

One 2 one Interviews – semi structured / structured – feedback impact

Focus Groups with users and carers about their views of mental health.

One off creative activities to elicit users and carers views.

Involving users and carers in setting up and designing a health care clinic, a hospital ward etc.

Designing the environment of a hospital, waiting room eg. Derby Children's Hospital.
Peer research programmes.

Involve users and carers in their treatment and identifying support – write client files collaboratively (report for New Zealand)

Create a Charter of involvement for services with users and carers.

Design questionnaires; enable users and carers to express what they would want to be asked.

Users and carers as trainers of participation for professionals.

Users and carers as peer researchers.

Creative Arts – Poetry, photography, painting and drama – eliciting views.

Users and carers as key members within conferences, reports, presentations.

Designing introductory video to services.

Designing service leaflet.

Users and carers as mentors to other users and carers.

Users and carers involved in recruitment and selection.

Members of Advisory groups or support groups.

Younger children;

Stories, Dolls and puppets

Painting and drawing

Conversation

Games, Junk Modelling

Action Plan:

- What are the opportunities for participation?
- In what ways is your organisation culture open to service user influence?
- What is your organisation prepared to change?
- How can participation be located alongside day to day practice?
- What are the next steps from here?
- What support would you need?

Action Plan should be SMART.