

Lived Experience Partnership Checklist

Where the goal is improved mental health for children of parents with a mental illness



This checklist is designed to be an easy-to-use reference tool for organisations incorporating consumer and carer participation (lived experience partnerships) into their practice. The checklist focuses on consumers and carers who are parents, as well as young carers and adult children of parents with a mental illness. The overall aim is to achieve better mental health outcomes for children of parents with a mental illness.

'Nothing about us without us' - where to begin

- Get in touch with other organisations actively undertaking consumer and carer participation strategies and learn from them.
- Know what your goal is, then involve consumers and carers from the *beginning*.
- Consider how to find participants (through existing networks, newsletters, flyers, posters, email lists, local newspapers, hospital and GP waiting rooms, etc).
- Consider mechanisms to reach people who have been recently diagnosed, and are at the beginning and early stages of their recovery journey, instead of only at the end of their journey (tips for this may include sending flyers to the services people may attend, or organising family activities from which you 'recruit' participants).
- Have support mechanisms in place for each individual participant (it is best if these are local to the person). Peer support is also valuable; see if you can link participants up with other participants for support.
- If the participation activity (focus group, committee, etc.) involves a group of professionals, make sure there is more than one consumer or carer representative so they can support each other and be sure their views are given the same weight as those of the professionals.

Working with families

- Consider how many people need to be involved and ensure a diverse representation of consumers, carers, adult children and young carers (e.g. mothers, fathers, grandparents, partners, young people, etc).
- Prepare participants with sufficient information about their role, including what participation involves practically as well as how it may affect their families.
- Consider the confidentiality of the whole family; will one person's involvement impact this? If so, support participants to consider these issues and to develop skills to talk about this with their families.
- If people agree to provide video or audio footage about their experiences, discuss confidentiality issues with them and be aware that although they may be happy to share this information now, at another time in their lives they may not feel the same way (this can especially relate to young people). Take time to discuss these issues with participants to enable them to make the right decision for them and their families. A consent form will also be required for audio and video footage.

Working with participants

- Develop multiple, optional mechanisms to involve participants (face-to-face, email, telephone, teleconferences, surveys, wikis, interviews, committees, phone-ins, etc).
- Use language understood by everyone; don't isolate people by using jargon or acronyms.
- Listen to participants, acknowledge what they say and act on their suggestions (to the best of your ability).
- Aim to develop processes for power to be shared with consumers and carers to enable them to make any decisions that are within their power to make. Be honest with participants about how final decisions will be made (e.g. their level of influence).
- Remember, people will come from different backgrounds and have had different experiences and some may have been traumatic. Get to know people as individuals and respect their ideas and opinions.
- Be clear with participants about what they are expected to do and be available to clarify questions. Have one person as a point of call for consumers and carers to contact, with a 'back-up' person if possible.
- Ensure that the benefits of participation go both ways and participants are given the opportunity to expand their skills, develop confidence and gain experience.
- Remember people will want to be involved at different levels on the 'ladder of participation' (informing, consultation, placation, partnership, delegated power, citizen control) and that this may vary depending on their health and the health and circumstances of their family.
- Start with goal ideas and processes and remember to progress to actions and outcomes. Then review your actions in line with the goals and processes.

Working with participants from diverse backgrounds

- There is a need for cultural awareness and an acceptance of cultural difference when working with Aboriginal people and people from culturally and linguistically diverse backgrounds (CALD).
- No one knows everything about other cultures; treat people as individuals and if you are unsure about something ask them.
- There are no magical answers, but the focus should always be on working in partnership.
- People from Aboriginal and CALD backgrounds can be a valuable resource to an organisation; bringing diversity and cultural insight into traditional methods of understanding and managing mental illness and engaging with diverse communities.
- For many Aboriginal people health does not just mean the physical wellbeing of the individual however, refers to the social, emotional and cultural wellbeing of the whole community (Swan and Raphael 1995).
- For some people from CALD backgrounds, the cultural stigma of mental illness may have major impacts on a consumer and their family, where a consumer may not feel comfortable disclosing their mental illness within their ethnic community.
- Remember to use trained interpreters where necessary. Not all people from non-English speaking backgrounds are skilled or qualified to be professional interpreters or translators.
- Ethnic radio can be a valuable resource to promote an organisation's participation program.

Doing it Right: tips for sustaining participants

- Ensure appropriate remuneration (for sharing time and knowledge) and reimbursement (for out of pocket expenses) is paid. This is an important way of acknowledging people's expertise and may also be vital to ensuring parents with young children are able to participate (e.g. reimbursement of transport and childcare costs). If you are unable to provide this, consider other ways of recognising their contribution (e.g. certificate of participation, let them know how valuable they are). Remember to include participation costs in any budgeting plans and funding requests.
- Follow up with participants afterwards. This should be done on the evening after the activity/meeting/interview, or a day or two afterwards when participants have had time to reflect – ask them what they prefer. Depending on the situation you may like to phone or email them.
- Participation programs need time to develop to their full potential and for people to feel comfortable; don't give up early.
- The previous point needs to be carefully balanced with the additional need to draw on an evolving pool of consumers and carers to ensure new voices continue to be heard.
- For participants ready to move on, help signpost them to other opportunities and projects (Robothom 2011).
- Evaluation of processes and outcomes is important, consider what mechanisms to use (e.g. feedback surveys, face-to-face reviews).
- It is vital to provide feedback to participants about the outcome of their involvement; take the time to inform people how their input was used and about the result.
- Remember the importance of trying to do the right thing, learning from your mistakes and trying to do it better next time (Clark, J. et al. 2004).

This checklist was developed by people with lived experience.

References

- Clark, M., G. J., et al. 2004. 'Cases for change: User involvement in mental health services and research', Research Policy and Planning 22, viewed 4th August 2011, <<http://www.ssrg.org.uk/publications/rpp/2004/issue2/article4.pdf>>.
- Robothom, D. A., Jo, 2011, Service user and carer involvement in the National Mental Health Development Unit, Mental Health Foundation (UK), London.
- Swan, P. and B. Raphael, 1995, Ways Forward: national Aboriginal and Torres Strait Islander Mental Health Policy National Consultancy Report, Commonwealth of Australia, Canberra.

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