



## How to develop a support network for families that is not dependent on EPI staff to convene

This information sheet was developed as part of the workshops held at the November 2014 *EPION Think Tank on Family Work*. It is intended for EPI programs in Ontario to use as a tool to promote discussion within their own organization and networks. There are 7 information sheets in total coming from the EPION Think Tank on Family Work. They are:

- Tips for EPI staff in working with families: What family members want you to know
- How to develop a family support network that is not dependent on EPI staff to convene
- Supporting families when their loved one comes in conflict with the law
- What other EPI team members need to know about family work: How everyone on the team can help support the family
- Choosing a family assessment tool
- Helping families at time of discharge: What do families need to know when their loved one is transitioning into the adult mental health system?
- Self care for family support workers

### About this Topic:

In many parts of the province there is little in the way of networks to connect family members dealing with a loved one with psychosis and the needs of these families are not always well addressed by other networks that exist around other mental health issues. This topic emerged from the desire of EPI program staff to nurture the development of peer led family networks. The following captures tips and ideas shared during the workshop discussion.

### Main Points:

- Psychoeducation should come before group support – this allows families to slowly become comfortable, learn and not be shocked by the stories of families who have loved ones with longer term psychosis.
- There is a benefit to both group and 1:1 peer support - Works for different people, different stages
- Need a “champion” to get the family peer led group going
- Peer support for families should include practical help (e.g. attending hearings with family, understanding forms)
- Peer family support worker could be paid or volunteer – can be hard to find a volunteer and then to retain the volunteer over time
- Family Navigators in hospitals – possible link in developing family peer services
- Need to find someone who’s enthusiastic-Family champions- keep asking and over time someone will emerge – getting the “right fit” would be important
- Need volunteers in pairs to share load
- Need to offer training to increase confidence
- Need clarity around role of peer support – (counseling, no med. recommendations, etc)
- Important to convey a hopeful message- stay positive-not consumed by stories about ‘the trenches’

## Other Ideas:

- CMHA York region has a successful family alumni group- it came out of cutting ties with EPI program at discharge - almost reactionary but has become a good thing
  - The group meets at a high school
  - Family volunteer run
  - Local EPI program refers to it at discharge
- Family Navigation Project
- Concern is momentum- need to have the numbers to sustain the group
- Staff feel a lot of pressure to make this type of group happen – is a challenge
- Spread geographically makes it hard in many areas to have a group such as this
- Would be very hard to find the ‘champion’ person who has the time/enthusiasm
- Having a list of names/phone numbers that people can access is good, however families are not likely to use this unless they have met the people first.
- One program facilitates a support group via OTN (offering some togetherness)
  - Down side - Need to be on camera- adjustment, some do not like, however there is the benefit of being able to see other group members
  - Families get to know one another and connect on own but still request EPI staff to facilitate, so it’s not really self-sustaining
- Families are also encouraged to attend consumer survivor group in community, depending on availability
- Many families need local options, convenient times, locations, appreciation of other life commitments.
- How to expand - who to go to as an ally, how to advocate for more support?
- First Episode families fearing “SSO’s name if there has been no diagnosis –this acts as a barrier to accessing SSO as a support
- How to find a skilled volunteer? – not a lot of options – big commitment – sustainability of a volunteer position is questionable.
- How to train facilitators? – Who? Mentors? Peers? Buddies?
  - Takes time to have volunteers feel comfortable
- Family members would love to have facilitators with success stories, to provide hope - benefit over professional support
- SSO offers to train all alumni from support group to be facilitators. Can train anyone across province.
  - First step: observe a group with a facilitator
  - 2<sup>nd</sup> step: 4 hour training
  - 3<sup>rd</sup> step: Co-facilitate with experienced facilitator
- One group member found tremendous support from Knights of Columbus, AA as well. Discussed that support can come from non-mental health organizations

- Idea: Closed Facebook group just for EPI families- alumni moderate it
- Idea: EENET- network for families- private forums
- Feasibility of moderation? Concluded that any online support will require a dedicated moderator who could be a volunteer
- Meeting families where they are at, needing positive stories, options for support. Need to gauge readiness for groups
- Education, peer support, buddy system **\*face to face is best, according to group\***
- Should programs advocate for a paid family support worker?
- Alumni Groups
- Jane Hamilton presentation (regarding some support people feeling unqualified) re: not needing to be expert-just listening and offering support and empathy is a powerful intervention
- Education and check-in in group may be a benefit to families that are in the same stage of recovery
- Family navigator, paid peer facilitators in hospitals, e.g. Grand River and St Joes Hamilton, is this an opportunity to leverage – partnership?
- Not enough to pass out phone numbers and emails – it was agreed that this will not sustain itself. Need to engage face to face first and have a “champion,” paid or volunteer