The Consumer and Family Toolkit
Modeling Collaboration

Developed by:

Mood Disorders Society of Canada

La Société Pour **Les Troubles de L'Humeur** du Canada

Principle Mandate

❖ The Mood Disorders Society of Canada is a national, registered, not for profit, consumer driven, volunteer health charity committed to ensuring that people affected by mood disorders enjoy the fullest, most productive lives possible, within a healthy, stigma-free environment

MDSC in the Community

- ❖ Virtual, web-based
- ❖ www.mooddisorderscanada.ca
- ❖ Web visits
- ❖ Advice and guidance
- ❖ Provincial collaborations
- ❖ Product reach – web; brochures and info
- ❖ Funding – private and public

GOALS for the Consumer/Family Toolkit

❖ If consumers and families were to be the 'centre of care' and 'collaborative partners' then their unique expertise needed to be valued and their information needs addressed.

❖ Toolkit was intended to provide a practical guide for engaging with the mental health system and in promoting becoming active partners in personal care.

❖ The toolkit was intended to raise expectations of service users on what their entitlements and responsibilities are.

❖ Toolkit was intended to educate consumers and family members on the value of becoming active participants in treatment planning and decision-making. Currently this is not widely the case and people need to feel they have both a right and a responsibility to participate in their care planning. They may also need to educate care providers on how this can be done effectively and respectfully.

PROCESS USED

❖ MDSC managed the project but it was guided by senior staff form existing national consumer and family organizations. If the toolkit were to have wide distribution within the 'target market' then it was important that each group felt a sense of ownership and commitment to its development. The process of the toolkits development reflected a collaborative approach to resource development that crossed diagnostic and organizational differences.

❖ Toolkits were developed on time and on budget within a very short time-frame. The process of developing the toolkit included an 'Expert Panel' of consumers and family members with experiential expertise who could provide a realistic view of the challenges people face in navigating the 'system' and useful advice of having their needs met.

❖ Experts were selected by national mental health consumer and family organizations based on their knowledge of the mental health system and the challenges faced by consumers and families. This made sure the content was practical, realistic and meaningful to the reader.

PROCESS USED (b)

- ❖ Expert panel included both consumers and families which created challenges based on differing perspectives and needs. Differences were negotiated respectfully and efforts made to find common areas of agreement while recognizing that differences do exist. This was supported by allowing an opportunity to discuss concerns openly and a consensus building process that helped people reach agreement.

- ❖ Focus of the toolkit was to build on existing resources and networks which are readily available on-line but still provide sufficient information to make the toolkit a stand alone document.

- ❖ Toolkit was intended to promote the value of peer-to-peer support for information exchange, advocacy and support. Readers were encouraged to take an active role in their own care as well as systems' level advocacy. Strategies for involvement were discussed.

PROCESS USED (c)

- ❖ Professional organizations had an opportunity to participate in defining the role that their professional group plays. It was important to frame recommended content based on the needs of the consumer and family member and what professionals groups had to offer and how people could realistically access those services.

- ❖ It was essential that the information reflected a consumer/caregiver perspective and not the views of mental health professionals. Gaps were identified in the content and structure of the web-sites of the professional organizations. Most were not consumer friendly and the information provided was targeted to meeting the needs of the professional group and not the service users. Although the toolkit directed the reader to these sites there may be little functional value in doing so. Addressing this issue was strongly recommended by the expert panel.

- ❖ Addressing the unique information needs of Aboriginal communities was identified early on and it was agreed that a targeted toolkit for First Nations peoples which emphasized their understanding of mental health and pathways to healing.

CONSUMER AND FAMILY INVOLVEMENT

- ❖ Professionals need to identify existing road blacks for consumer/caregiver involvement. Consider engaging the consumer and family organizations to undertake an audit of your service from the perspective of the service user to provide you with recommendations for improvement and provide a benchmark from which to measure change.

- ❖ Add an evaluation process or 'customer satisfaction' tool into all work being done. Review findings regularly and make appropriate changes when there are system-level issues needing to be addressed. Report finding and action taken to patients to build their sense of empowerment and efficacy.

- ❖ Develop and promote a policy framework that imbeds including families in planning and treatment planning processes. Currently professionals hold the misplaced view that they are violating the 'rights' of consumers by having contact with family - often without even asking.

CONSUMER AND FAMILY INVOLVEMENT (b)

❖ Provide 'care partnership' handout to patients and families that allow them to define their goals, treatment expectations etc. to ensure there is a shared agreement regarding goals i.e. recovery vs symptom reduction. Review care plans regularly to measure success.

❖ Provide more consumer-friendly educational resources to provide take-away information that encourages self-directed health promotion and illness management.

❖ Remove the professional jargon from discussions, writings etc.

❖ Learn about the recovery movement and check your messaging that does not reflect a hopeful approach to health, wellness and recovery. For example "This is a chronic, lifelong illness for which you will always need to take medications".

CONSUMER AND FAMILY INVOLVEMENT (d)

- ❖ Hire consumers and family members as part of the team – peer to peer support etc. to break down the 'them vs. us' thinking.
- ❖ Make more time during appointments to allow patients to be able to ask their questions.
- ❖ Encourage patients to include caregivers.
- ❖ Encourage consumers and family members to be involved in Boards, committees and working groups as equal members.
- ❖ Put out a 'welcome mat' for consumers and family members on websites and in contacting your organization. Have a knowledgeable staff member designated to answer inquiries effectively and record common questions or concerns. Create a 'frequently asked questions' section of the website.
- ❖ Make sure the process of complaint and appeal are clearly stated and easy to access and that each patient is fully aware of the availability of this.
- ❖ Have a consumer/family ombudsman assigned to address concerns.

INCORPORATING THE USE OF THE TOOLKIT

❖ Read the toolkit and incorporate messaging regarding involving consumers and families in care conferences into their practices. Set benchmarks regarding how often this is currently being done and measure changes over time. Evaluate.

❖ Add the toolkits to your web-sites using a consistent CCMHI icon to build 'brand awareness.

❖ Disseminate toolkits through your existing networks, endorse and encourage professional to make them available to their patients and families.

❖ Make toolkit available through your public education events, workshops and conferences.

❖ Invite consumer and family members to participate as experts in educational events and training activities.

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