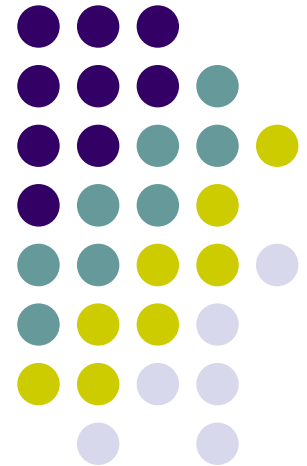
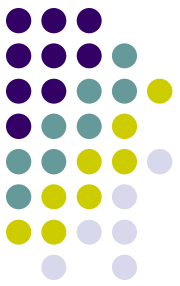


QUALITY OF LIFE...

Defined by people living with schizophrenia & their families

PREPARING FOR A NEW ERA
Florence Budden & Neasa Martin
CFMHN National Conference,
October 21, 2009





Purpose of the survey

- Add depth to the SSC mission.
 - Identify priorities & elements of QOL
 - Inform SSC education, programming & advocacy.
 - Strengthen voice of consumers & caregivers.
 - Inform work of the MHCC
- 1,086 participated in total
 - 433 consumers, 572 families / caregivers
 - 8 focus groups (Alberta/Ontario/Quebec/NF)
 - 72% families use/have used SS's
 - 66% consumers use/have used SS's



Critical for QOL - both agree

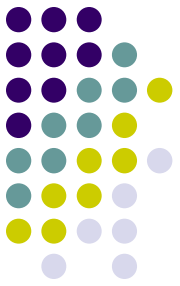
- The support of family & friends
- Positive relationship between caregiver & person with the illness
- Meaningful, productive, satisfying work
- Purpose, meaning & balanced lifestyle
- Acceptance & involvement with community
- Self care is crucial
- Access to timely supports & services

Critical factors are often not in place





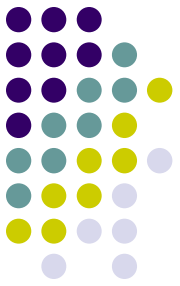
Medications & QOL



- 91% taking medication & ranked as very important
 - Control of illness does NOT equal QOL
 - Medications enables QOL → adherence to treatment
- People are ambivalent about meds (58% feel it limits QOL)
 - Professionals ignore, minimize, don't take concerns seriously
 - Families agree complaints are real & ignored
 - Professionals & families place too much reliance on meds.
- Both want access to newer medication - costs covered
- Both want more research on medications
- Some families want more legal control & forced treatment



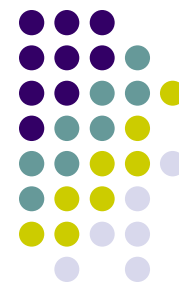
Supports & Services...



- Want not just MORE - but DIFFERENT supports
- Both want 'recovery-oriented' services
- Message of hope & optimism- not a 'life sentence'
- To be treated like people - not a diagnosis
- Attention on symptom management not good enough
- Focus on enhancing QOL
- Include natural support network (family, friends)
- Social inclusion outcome goal



Limits to QOL



Families

- Personal impact of illness (burden, worry, frustration...)
- System failures (access, exclusion, unresponsive)
- Alcohol & drug use → violence & withdrawal of support

People With Schizophrenia

- Poverty & unemployment - linked to barrier to QOL
- Social exclusion due to stigma & discrimination
- Poor health, symptoms of illness, side effects
- Depression, loneliness, lack of meaning
- Pessimism of others



Differing perspectives...

- Both share optimism & hope of recovery
- Families see **↑** limitations & **↓** QOL
 - Want more - not enough being done
 - Sacrificing QOL to provide support
- Consumers more satisfied with their QOL
 - More accepting of illness & limitations
 - Building a life - recovering 'new sense of normal'
- Families more willing to speak with others
 - More pessimistic view of QOL, limitations & needs
 - This may increase stigma & discourage recovery

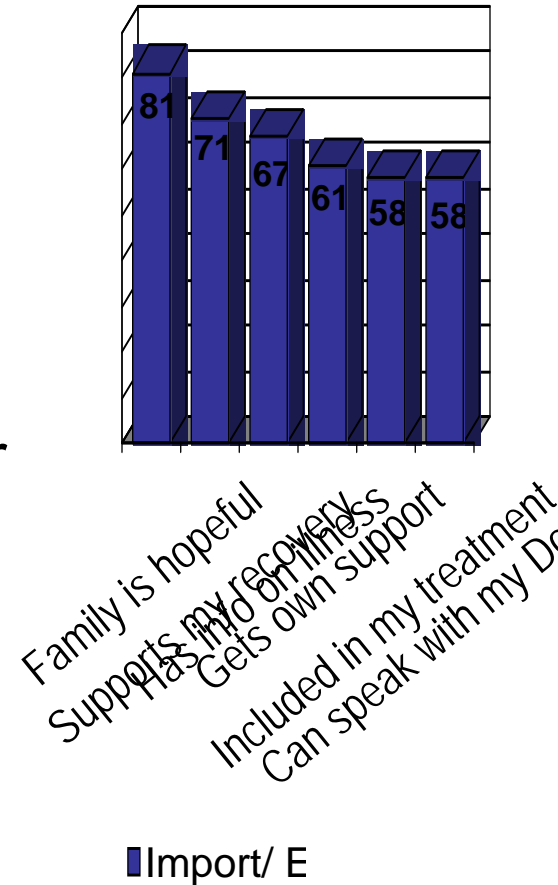


These differences confirmed in focus groups

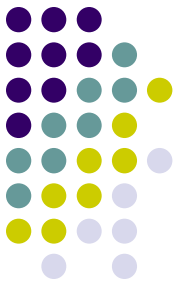
What consumers want from family



- Not all families are supportive
 - Develop own 'family' - including peers.
- Need families to be hopeful & support their recovery
- Need non judgmental support
- Patience - recovery takes time
- QOL is intertwined - one affects the other
- Families need to practice self care
- Families need to begin their own recovery journey

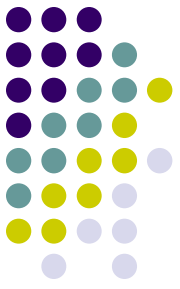


For Healthcare Professionals...



Survey implications...

- Meds. important - but QOL is MUCH more
 - Meds. bring problems & solutions
 - Too much focus on meds. - not enough on QOL
- Focus on strengths - less on limitations
- Be hopeful - see the person first
- People *need* multiple supports - aligned to meet goals
 - Listen more, judge less, treat with respect & compassion, include in treatment decisions
 - Teach skills - coping, life skills. Support independence & encourage choice. Help practically - finances, forms, housing...
- If you help the family - you help the person
 - Include families in care, provide information, practical & emotional support



For Healthcare Professionals...

- Make hope, optimism & recovery key messages
- Develop recovery-oriented educational resources
 - Emphasize early intervention
 - Peer support is critical - provides support, acceptance & meaning
 - Support employment, education, volunteerism, & empowerment
 - Teach skills: control illness, social & independence ADL
 - Help navigating 'system'
- Address stigma, discrimination & social inclusion
 - Through education, policies & promotion of rights
 - Enhance consumer supports - serve as a bridge to community



For Healthcare Professionals...

- Support self defined QOL goals
- Align Advocacy work as an organization / healthcare professional to maximize QOL outcomes
- Make employment a priority – remove barriers, build bridges to school, training & work
 - Emphasize the support of friendships, family and community connections as core to attaining QOL
 - Peer-support plays a valuable role in QOL
 - Advocate for health system reform that align with recovery-oriented outcomes
 - Advocate for funding of safe, affordable, secure housing



Messages for SSC



From consumers...

- Recovery is possible! Convey a message of hope & optimism.
- Work is core to QOL:
 - Poverty & unemployment is an important issue
 - We want to make a meaningful contribution
 - Remove the obstacles (pensions) & build bridges to work (peer support)
- Deal with stigma & discrimination:
 - See us as 'people first', not as an illness
 - Use a positive focus - what we can do - NOT what we can't
 - Protect our rights - we are all equal
 - normalize schizophrenia, educate public, address the myths - particularly issue of violence



Questions... Ideas...
Comments...

