DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
Social Recreational Empathetic administrator at social clubs, rapport, safe, healthy environment for gathering, a variety of accessible programs & activities, a comfortable & welcoming atmosphere (home like) – dedicated and involved club members, regularly scheduled activities and meetings for keeping members well informed – variety of social / recreational opportunities in the community -	Disrespect, lack of communication, "turf wars", discrimination (social, ethnic, racial, religious, economic), too few options & opportunities, disregard for confidentiality, stigma associated with mental illness (we need to be IN the community, not segregated from it) – lack of structure – when the consumer voice goes unheard – we have lost good programs because of loss of Maine Care money for them	More equitable division of funds among social clubs – create more options for everyone, not just those who can go to the clubs, use community space for gathering, Integrate into the community – make options more appropriate for individuals and what they like to do – encourage more community involvement – use volunteers & mentors – develop and support consumer operated mentoring programs – one statewide toll free number, website and/or newsletter for recreation opportunities (state should fund resource position) – consumer-run boards could prevent tokenism – access to transportation for events – we need education on social skills and how to be in society – reduce stigma by removing signs on state property that send out negative expectations – Mobil entertainment, art. Dance, etc. – outdoor activities such as *Venture Group; Breaking the Barriers*;
Financial Rep payees (MOCO) – Maine Care IF you qualify – sometimes voc/rehab - shelter plus care – section 8 – Bridging Rental Assistance Program – SSI – SSDI – PASS (Program to Attain Self Sufficiency – budgeting skills – learning basic financial skills – Human Service supports if you qualify	Inflexibility of the system – lack of safety nets for those who try to change their financial circumstances – lack of trust – incentive programs have no incentive – SSI-SSDI – the poverty paradox (the consent decree says we should not live in poverty but the system keeps us there – no timely answers to questions that are time sensitive (or no answers at all) – limited resources – balancing the state budget on the backs of the disabled – people who get married experience financial disincentives and lose services – government actively penalizes spouse for partner's funding – penalty is based on level of disability	More tax equity to raise revenue – better training and education for providers so services are more cost efficient – provide opportunities for consumers to move forward in their recovery – regulations more humanly oriented – information provided in "user friendly" language – financial advocacy needed at all levels – state & federal government should redistribute funding based on meeting basic human needs first – stop putting out fires and promote wellness – a long range plan – Income waivers so people can save in order to better their housing and education – Individual Development Account (match for saving)

DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
Crisis Trained mental health workers who work side by side with police in some areas -	Dealing with outsiders (police & crisis workers) – Emergency Room issues/ Lack of training in the emergency room – long waits with no empathy or support; put in a room and forgotten – NOT being able to reach your worker, therapist or psychiatrist in time of crisis – when we go to see a crisis worker and are put directly into the hospital without seeing the worker - having someone else determine my level of crisis – when a pill is the answer instead of just listening – Police make you feel criminal rather than ill	Peer support at the emergency room – 24 hour drop in peer center with a phone and staff & volunteer support – extended phone number to the warm line so people can call when warm line is closed – transition services for hospital releases – peers to make calls and visits after release from hospital – peer resource centers in each region and both state hospitals – IN-home support during crisis – training – peer support – community education – advance information – assistance to create better crisis plans – alternatives to hospitals – better communication – training on women and aggression – find a way to shorten the wait lists so we don't have crisis – transitional housing when leaving the hospital -
Hospitalization Community volunteers, peer support, in emergency rooms / visitation – the hospital is a safe place – properly trained medical personnel – meditation rooms to go and be comfortable – when there is a connection between our care in the hospital and returning to the community (continuity) – appropriate level of care throughout the stay – follow up care – ambulance & EMTs – follow the advanced directives -	Inhumane and disrespectful treatment – if we call crisis the cops come – NO respect for personal privacy or circumstances of your hospitalization – segregation – insufficiently trained personnel –lack of "quiet space" – seclusion & restraint do NOT work; a quieter, gentler approach is needed – Using the most drastic measures first – ignoring the advanced directives – lack of follow up after discharge – when services are interrupted, new personnel are assigned – rapport with previous workers - quality care is rationed by ability to pay (insurance) – private care favors payment – lack of choice (food, diet) – lack of holistic treatment – sending us far from home for a hospital bed	Assign security guards as observers and mentors to talk with you and listen while you are waiting to be seen – keep community providers involved with care & treatment – sensitivity training, especially in cases of trauma and suicide – better atmosphere) – personalized care (treat people like individuals) more affordable healthcare – crisis respite services – community support – organized crisis/trauma volunteers – better facilities (more like a normal atmosphere – true discharge planning with follow up that involves community support providers – no one should ever be denied care based on ability to pay/based on need

DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
Spirituality Daily meditation books (e.g. for AA, NA, Dual Diagnosis, etc.) – using spirituality as a clinical tool with proper training- spirituality groups -	Access to spiritual activities limited due to lack of transportation – no significant attention to spirituality in ISPs and therapy -	Give individuals a chance for alternative treatment – provider training for spirituality groups) – open mindedness - training – empathy for the views of others – buses to run on Sunday (and longer hours) – Others to realize the impact that spirituality means to us -
Medical Holistic and alternative medicine Research Clinical trials	Not much if the governor cuts the budget – transportation is unreliable – support and assistance in making arrangements on time – incorrect communication – when the psychiatrist and medical doctor are in conflict about care – medical staff insufficiently trained about medication and side effects – Maine Care and the way they handle drugs, for example …doctors prescribe a particular type or amount of medication and changes in the prescription are made because Maine Care won't pay for what was ordered. When we are in the hospital and getting better on a particular medicine, that may suddenly change on us when we leave – that creates a problem for us. – having NO information on how to keep Maine Care while getting a job – Hospital stay time limited by pay sources – It takes 2 years to get Medicare	Better transportation – Keep Maine Care after you get a job until you get insurance from the job – more preventive medicine – transportation for crisis appointments (NOT police cars) budget for it- – therapy should cross over crisis, hospitalization, nursing home, etc. – Let psychiatrist prescribe what is needed and MC stay out of it – better one to one advocacy – get a dental & eye plan – better training and education – let us have a wellness program so that we won't get sick or have dental problems that take up the budget

DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
Community Support **Case Management** Setting goals Support in getting to appointments Help with financial responsibilities Support in deciding what is best for me Having a choice of whether to have one Having case manager close Flexibility to help deal with daily obligations Willingness to transport for those without transportation or special needs, etc. Continuity when it works ICM has helped with moving, transportation, appointments -	Having to relocate-to get case manager Not having a choice of whom you have Lack of communication-setting an appointment but not writing it down correctly Flexibility-not coming when you need them Continuous cancellation-feel not worth anything Being put on a waitlist Not checking in when on a waitlist Management not responsive to concerns-complaints about case management (grievances) Treatment on waitlist-being humiliated ISP-useless because case manager not want to work with Not having Medicaid—don't get help they need Changing workers Having to go to several agencies to get all needs met - when I have to spend more time giving the case manager personal support than they spend helping me –	Hire more case managers (Hancock County) Better training in developing & maintaining good working relationships Simplify paperwork-number of people needed to get services should be reduced Having referral process meet needs of consumer Training in dealing with trauma issues (accept that it exists) Prioritize waitlist Agencies be consistent in providing case manager—not switching consumers Sliding fees – flexibility Bridge relationship between Hospital & Community on consumer's behalf Info on Website by provider on case management-shop around Continual feedback loop to QI for agency & BDS Equal opportunities for work & schooling Being treated with respect as equals in the system, including honoring choice without judgment Follow ISP as equal collaborators Review ISP on time without having to back date Consistent expectations across agencies Lose the psychobabble & speak English For every visit with CM consumers should get a paper defining the length of visit, comments, visit description (sign off) - –(*it is hard to sever ties with case managers when they do a good job –we need help with that)*

DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
Out-Patient Services Good therapists-making themselves available for when you need them Listen, supports available, respect, positive support, knowledgeable, trustworthy, and skilled Access to groups/clubs Access to good medical care	Unnecessary med clinic appointments at cost to client or MaineCare Prior authorization requires changed meds-less costly-pay for cheapest/not what works or is prescribed No freedom to self-pay for what works (if we have a med that works & want to pay for it ourselves, we can't - supplanting Medicaid) Not enough access to good Medical care-lopsided allocation of resources (urban vs. rural) Lack of education re: Illness, Medications side effects Cuts to what will be paid for-day program	Education on self-advocacy Education on meds, illness, symptoms More $ for what works Allow doctors to prescribe instead of insurance companies Consistent meds from hospital to out patient Better access to good medical care Meds not used as control tactic including overmedication Respect consumer's experience
Psychiatric Services Good relationship with therapist-communication Guidance about what to do—help walk through it Availability to transportation to get to appointments Receiving samples of meds until see if it will work Education about illness and how meds work & side effects Honesty re: illness/being upfront-don't hide anything Working with you as an individual & whole person and not just a diagnosis	Not having choice of doctors—insurance related Not listening to consumer feedback about whether med is working or not/how it feels-take seriously what say Too long a waitlist for a psychiatrist (especially when in crisis) Lack of communication-not calling back Breaking confidentiality	Shorter waitlists—increase number of psychiatrists Be a good listener—treat as individual More MaineCare approved psychiatrists Education on how to support individual recovery Support consumer self-responsibility Keeping confidentiality unless safety is an issue Respect for one another—partners in treatment · Have rights about choosing psychiatrists ie: Male vs. Female---what fits

DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
Housing If there is an emergency one goes to the top of the wait list – subsidized – adequate notice for inspection; polite, courteous, respectful – shelter plus care – energy assistance – when the size "fits" and location is by choice – being able to live with children & other family members as desired -	Quality varies – location not convenient to services, shopping or supports– living in a building with age groups that I don't choose – cosmetic problems – physical challenges (3rd floor) – it is impossible to live within my means, do what I have to AND have my children – accessibility/transportation -	Housing should fit for sociability (people stay over, grandchildren visit, etc.)- housing wait list policies should include top priority for people awaiting discharge from psychiatric hospitalization and people who have been evicted because of situations stemming from extreme emotional distress and people at risk – we need more education for consumers concerning all housing programs (especially subsidized) – More renovation of Maine's old housing stock – more residential apartment buildings with on-site support staff – Have parking space requirements in favor of good transportation – Housing solutions must be developed for people with children that respect the family
Vocational Rehabilitation Many responses indicated that nothing works – education – marketing ticket to work	Losing good VR counselors (transfers) – They thought I had too many problems to be rehabilitated – my job experience didn't work – lack of individual plan – I could not achieve the amount of work that was expected of me – I was never offered services – lack of follow up, dedication, money – workers are in control of their own budget and sometimes show client favoritism at the expense of others – no accountability – being offered a job and finding out there was NO funding available – Rules of other programs (ASPIRE) interfere – NO personal plan	VR should do outreach to all BDS consumers – VR should be more flexible in accommodating the needs of consumers – VR should structure funding so each consumer understands his/her choices & options – VR should carefully workup individual plans with the consumer – VR services must be monitored for quality by an outside organization

DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
Access to Peer Voice Citizens Access Network (computers); this program is no longer in full operation due to lack of funding – access to resource information and support in establishing membership at policy tables, etc.- learning skill – opportunity to speak at different organizations – formal training by consumers for cross system people – direct communication to decision makers and the larger community – statewide consumer driven advocacy network -	Pie syndrome – limited resources, huge need – information is not timely or in understandable language - transportation cannot be arranged in a timely manner in order for people to get to the tables -	More affordable access to technology for networking, information sharing, training, communication, leadership, etc.- formal working agreements among consumer/provider/state agencies to increase consumer access to information and decision making (more publicity - strengthen relationships with media regarding meetings, etc.) – provide training & mentoring for consumers who hold positions of responsibility in order to ensure their success – provide sufficient resources and operational support for statewide advocacy organization to truly reflect state – conduct policy meetings in a user-friendly way – eliminate buzz words – educate leadership to facts & research that INFORMED consumers make better choices (cost effectiveness) – create licensing regulations that place consumers on all agency boards of directors & BDS program & policy development tables – monitor adherence of Quality Improvement Council and block grant policies regarding consumer involvement -

DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
Obligations - STANDARDIZED ASSESSMENT – Quick & efficient – assures that all the right questions are being asked across the state – fairness to get treatment – objective – gives demographic of needs in different parts of the state – gives data for present future needs – can track an individual's changes in intensity -	They are degrading & dehumanizing – there is no established national or state scale to determine "what is acute" – eliminates the principle of individualized treatment by not addressing the issues and nuances of the person – "Because of standardized assessment, I lost my case manager services; historically the system always messed up my services; I see no assurance to get help right away if this happens again." – I was told I no longer needed a case manager; 3 months later (THE day I left a 3 ¾ month hospitalization) I was told I no longer had a case manager (November 2003). The case manager (I had not seen for all the hospitalization) came to the hospital and said "Goodbye". GAF – GLOBAL ASSESSMENT FUNCTION – This definitely does not work! If you score 49 and below, you get to keep provider services; 50 and above, you transition out of services. On a GOOD day I was a 92, and on a BAD day I scored 40. This does not allow for individual circumstances or support people when they are doing well. This is not something you can use to classify someone's services or service needs.	All SA consumers should be able to choose providers; concerned persons, peers, etc. give their opinions concerning the consumer's needs. – SA forms must have a section for consumers to write their perspective concerning what services they need and why - Consumers must participate in the development, presentation and quality monitoring of CSW training concerning "humanizing" individualized standardized assessment and treatment plan.
PROCEDURAL BLUE PAPERS "Misuse of Blue Papers" how would the consumer be sure, or even know they didn't need the Blue Paper?	Abuse of power – "I was voluntarily in the hospital. The weekend "on call" Doctor refused me any family visitors, when I strongly objected, I said I would leave – The Doctor threatened Blue Papers even though I was voluntary (April 2003) – 4 weeks ago a family member agreed to be hospitalized – the Doctor blue papered because of a history of leaving AMA (against medical advice) -	

DOMAINS WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
ISP – INDIVIDUALIZED SUPPORT PLAN FORM Section 1		Rewrite – may or may not want csw's assistance
Section II	Goals & policies do not support individuals who are very ill, but posses high functioning life skills. (e.g. "I had major depression and I needed to feel safe because of suicidal ideation around using the stove, and loss of focus by leaving the stove on and burning pans. I was afraid to cook my meals. When I asked to get in home support I hour daily to assist me to cook until I was better, I was told they couldn't put it on my ISP because I already knew hoe to cook."	
Form is easier to read; may be easier for the worker & consumer to use – Good if uniform across the state –	Boxes are too small	
ISP – INDIVIDUALIZED SUPPORT PLAN PROCESS Allows for greater creativity in finding resources, services – individualized – I get to voice my own ideas – it is a tool to help me clarify – I like the section where I can see my agency, BDS service plan – when well used it gives CSW more time to work with consumers	We are locked into the ISP – it is on paper – does not allow for variance of intensity – system "thinks" recovery is on a straight line to "cure" and try to discharge people from services prematurely – they use the goals against us – there is no room for relapse & the CSW caseload doesn't allow for "intense" periods of time – They ask us to backdate the ISPs – system continues to retraumatize, using the ISP as a tool to do it! - the ISP is used as a smokescreen for consumer driven and individualized – when CSWs do not understand nature of mental health & ISP has no flexibility for goals, actions or services –forced to do casemanagement, CSW services	Independent, external organization to monitor ISP effectiveness – Peer developed and delivered ISP training Unmet needs must be taken seriously as individualized service treatment – Holistic needs keep people healthy
	CSWs all have different ideas of "what helps" – common sense things – agencies blame consumers as a failure and for being enabled when services like transportation, shopping	

DOMAINS	WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
		and help cleaning don't exist – spouses, family, friends, churches and guardians who want to be involved are ofte Services –tally ill parents receive no support for children's needs in the ISP process – Consumer's child can't be with their mentally ill parent if parent is being transported & no child care is provided -	

DOMAINS	WHAT WORKS	WHAT DOESN'T WORK	SOLUTIONS
CROSS SYSTEMS ISSUES FOR CLASS MEMBERS			
COUNTY JAILS		Consumers who are in jail do NOT get their medications when they should, One example includes a class member having meds delivered to the facility, but NOT receiving them until 6 days later – Mental health liaison workers not following up on promised jail visits – Same person takes powerful nighttime medication (2 prescriptions) and was penalized for not getting up quickly enough when their morning meds were delivered to them	All of these systems need checks and balances for accountability –
DHS		Class members who have DHS guardians are at the mercy of their guardians who are NOT well trained in their issues – some retraumatize consumers by making them feel unsafe and unsupported – one example is a woman who had her own apartment successfully for 5 years being unnecessarily removed from her apartment and sent to a restrictive boarding home over 40 miles from her family. She was told that she was being taken out to breakfast, but instead never was taken home. She did not have clean underwear or clothes for over a week, until her sister had money to get some for her & delivered them. She lost her apartment and her freedom. –	
CORRECTIONS		Probation officers do not understand the impact of mental health issues. Some ridicule those who have this situation and some discriminate against us.	