Confidentiality, Integrated Services, and Recovery

(2011)

In its most traditional form, the professional treatment relationship is clear and comforting: You come to me as a professional in a time of need and willingly share information with me you normally might keep secret making yourself vulnerable. In return, I agree to: 1) Keep your information secret, 2) Protect you and take care of you, and 3) Use my power to help you. Maintaining confidentiality is a crucial component of the treatment covenant. Without it trust will likely be lost.

Nonetheless, confidentiality has numerous limitations, some imposed by statue, some by case law, some by signed waiver, and some provider-driven to be able to help people practically. If we reflect upon it, maintaining pure confidentiality is always impossible. Confidentiality routinely conflicts with many other mandates and often also with our ability to help people and, as a result, regularly needs to be thoughtfully compromised.

To begin with, the best way to keep a secret is not to write it down or tell anyone else about it. Yet our daily practice requires writing down treatment notes and sharing them with a variety of payors, auditors, and administrators. Soon it will require electronically recording them into systems that many people, unknown to us, have access to. This gives us the additional responsibility of securing those written and electronic records, a formidable task.

Being part of a public mental health system requires accepting administrative oversight and coordination with the system as a whole. We record our contacts, diagnoses, prescriptions, and people's financial, demographic, and contact information into systems that hundreds of other people have access to. When something particularly sensitive happens, instead of being more secretive, we are required to write incident reports and submit them to DMH administration.

Many of these other people do not have as their major purpose helping patients. Some are focused on saving money, some on protecting the system from liability, some on protecting people from their providers, some on promoting certain public people and policies. How are we as providers really supposed to maintain our treatment covenant in the face of all this outside intervention?

Every time we get someone else involved in the person's treatment, for example by doing a lab test, or hospitalizing someone, or accessing some government entitlement program like SSI or vocational rehabilitation, confidentiality is further eroded. Yet good practice requires us to do all of those things with everyone. These are referred to as" business partners" in HIPAA regulations, but we can easily acquire an unknown new "business partner" for example when someone takes a prescription to a new pharmacy or moves to a new Board and Care or joins a new HMO.

The criminal justice system places further responsibilities on us that conflict with confidentiality. Sometimes police want help in tracking a suspected criminal before they victimize someone else. The judge in the Tarasoff case said that even if there are no grounds for involuntary hospitalization, we have

a duty to break confidentiality to warn and protect potential future targets of people we serve. Judges, probation, and parole officers routinely turn to mental health providers to enforce criminal penalties and to report to them whenever someone fails to meet sentencing and incarceration diversion requirements.

Society as a whole adds even more conflicting responsibilities, requiring us to protect society from the people we serve, for example, by reporting them to the secret service if they threaten the president, or to the DMV if they are an at-risk driver, or to adult protective services and child protective services if they endanger someone else. We're even required to violate confidentiality to protect the person themselves even if they don't want us to.

As providers seek thoughtful compromise between all of these conflicting mandates, each proponent seeks to enhance their status, not by arguing their relative importance, but by increasingly threatening providers. Auditors threaten to take away funding or press criminal fraud charges, judges threaten with subpoenas and contempt of court charges, and HIPAA threatens us with license removal and jail time. As if that's not enough, they threaten program administrators to get them to influence their providers.

It is up to us to resist all these threats and return to the" reasons behind the rules" and our covenant with the people we serve. The primary reasons to protect people's confidentiality are:

- To avoid shame and embarrassment from having information revealed
- To avoid negative consequences of their actions
- To avoid negative consequences and reduced access and opportunities from stigma and prejudice
- To avoid being victimized by someone else misusing their information
- To avoid damaging trust in us limiting our ability to help them and emotionally retraumatizing them
- To prevent unwanted intrusion of others in their services, lives, and choices

These are serious reasons and should form the basis of our daily decisions rather than weighing the various threats being leveled against us.

How do integrating services and community integration affect this picture?

MHA believes that:

- Almost everyone needs more than one service and one provider to recover
- It is better for multiple providers to be coordinated and work as a team than for them to be fragmented and isolated from each other
- Peer support can be powerful
- Breaking down barriers between providers and the people we serve and actively hiring consumers empowers people to recover
- If we're going to effectively help someone not just to be less ill, but to actually have a better life we have to leave our building and work in the community

- Sometimes our job goes beyond helping people to better get along in our community to help our community become a better place for people to get along in.

Implementing each of these principles impacts confidentiality.

There is a step-by step progression as the integrated circle widens:

1) When we move from one provider to a team of providers, it becomes difficult for any given provider to "keep a secret" from the rest of the team. We often explain that limitation in advance. People may complain that one provider they conflict with may be spreading distorted or selective information about them biasing other staff against them. If one staff on a team harms a member, it may be difficult for other team members to report them to protect the person. If the offender is a supervisor, team leader or psychiatrist it can be even harder. This is the scenario in which the HIPAA urges staff to report team mates and supervisors to authorities outside of the agency.
2) When we move to multiple people being served by the same team of providers in active contact with each other, encouraged to support each other, confidentiality is more like in group therapy or a 12-step meeting than in 1:1 treatment. The entire group is expected to respect and protect each other, but that's a far more vulnerable position than 1:1 treatment.
3) When the barrier between people being served and providers is intentionally blurred, the line between what information only the provider staff knows and what information the peer group knows is also blurred.
4) When we reach out to include other service providers, we have to share information with them as well. This usually requires a confidentiality waiver, but the person is under substantial duress to agree if they want to access additional services. We may choose to only provide information "they need" rather than comprehensive information. Sometimes people want us to refrain from disclosing something to retain their eligibility (for example don't tell Social Security about drug abuse, Board and Cares about fire setting or bed wetting, HUD about their under the table job or the boyfriend they have living with them. We may have to balance confidentiality with the integrity of the other service provider and our relationship with them.
5) When we reach out to families and friends, many of whom are profoundly affected by what the person does and many of whom are critically important to the person's recovery, we enter a potential minefield where confidentiality may be used as an artificial tool for relationship or power reasons. Providers may be tempted to use their own judgments as to the positive or negative influence of these relationships as we make confidentiality decisions.
6) When we reach out to other community members, like landlords, employers, recreational groups, and churches to develop opportunities for members we may have difficulty disguising ourselves to do truly "nondisclosure" development. We may also be able to develop some community opportunities, say with rent guarantees or "we-pay" internships, only by compromising confidentiality.

Taking each step along this continuum is likely to increase our impact on people's lives and their opportunities for recovery. On the other hand, each step is also accompanied by decreased autonomy, privacy, and control for both providers and people being served. Either or both commonly refuse to

take the next step because they don't want to lose autonomy, privacy, or control. The principle of "client driven" services would lead to more of those decisions being made by the person being served instead of by the provider. The more steps we make in this continuum the more aware of confidentiality we have to be, not the less aware, because we are intentionally taking more risks.

How does recovery and resilience affect this picture?

The recovery model builds a very different treatment relationship replacing the three responsibilities I began this article with six transformed responsibilities. Maintaining confidentiality is not as crucial in this treatment covenant, but can still have a powerful impact:

1) **Help people trust us**: Trust is often built more with self disclosure, shared humanity, open caring, charity, and supporting client-driven goals than with protecting privacy.
2) **Help people regain control of their lives:** Whereas traditionally providers help control a person's life for them, in recovery relationships it is crucial for the person to regain control of their own lives. This makes personal choice the more crucial component in confidentiality decision than secrecy. From a recovery point of view, it is almost as bad to withhold information from someone in their life or exclude them without asking the person as it is to share information or include someone without asking them.
3) **Help patients rebuild their lives:** To truly support rebuilding a life services must progress along the continuum on the previous page. Each step necessitates compromising confidentiality. On the other hand, the further we widen the circle, the more likely the person will suffer negative effects from disclosure and resultant stigma. Doing proactive community development work to decrease the destructive stigma in our widening circle can decrease the harm people face from disclosing mental health information.
4) **Help people heal from destruction and rejection:** Healing from destruction and rejection can initially be facilitated with a highly private 1:1 relationship, but there are clear limitations to generalizing the healing from that approach. By contrast consider the power of the 12-step group approach where people share their experiences of destruction and rejection in a highly accepting, inclusive, respectful, appreciative atmosphere and are healed with mutual listening and applause. Some people gain enough healing to proudly display 12-step bumper stickers for the entire community to see. Getting to that point of sharing information instead of maintaining confidentiality can become a milestone of recovery.
5) **Take the long view:** Decisions about breaking confidentiality and sharing information should actively consider the long term impacts and not just the short term utility.
6) **Help people move on:** Maintaining tight 1:1 confidentiality can seriously handicap people's efforts to successfully move on. If only one provider knows important information, or "really understands me", or can be trusted, a serious dependency on that provider is likely to develop and surviving their loss and moving on will be more difficult.

Once again, we would hope that this progression in the recovery relationship, and with it the progression of confidentiality decisions, would be driven by the person instead of by the provider.

Recovery emphasizes building strength and resilience instead of relying on reducing deficits. This principle can also be applied to our approach to confidentiality. The standard approach to confidentiality is to be protective, to avoid situations where the person would be vulnerable to harm and where they're actually harmed. Instead of relying entirely on a series of "thou shalt not" confidentiality prohibitions, we can incorporate a series of positive, proactive, harm reduction measures. In many ways this is the more realistic approach since, as we have seen, perfect confidentiality risk protection is impossible. Here are some possible resilience building strategies:

- Write chart notes in a way that they can be actively shared with people without shaming them or damaging our treatment relationships. When people know what's in their charts they can also make better disclosure decisions and profit from those decisions.
- Actively work with people to take control of their illness and recovery narrative so its disclosure is not shaming or feared.
- Encourage and prepare people to take responsibility for consequences of their actions instead of relying on hiding from them and avoiding them. Help people make better decisions so there's less to hide.
- Work on decreasing stigma and prejudice both in our community and within the person themselves. Build acceptance of their illnesses, lives, decisions, and selves.
- Help people learn to trust us and others based on other factors besides the ability to keep secrets.
- Help people build healthy, interdependent relationships so they're less dependent on us and less fearful and avoidant of others who care about them.
- Help build a culture of mutual respect in our programs and our communities so people are less likely to victimize each other even when they have an opportunity to do so.