How To Protect an Individual’s Privacy Regarding Healthcare and Health Information

Privacy is important for all persons. People have an expectation that they should be able to make private decisions, have privacy in their homes, and have information regarding themselves protected from sharing with unnecessary or unintended third parties. New Mexico Administrative Code 7.26.3 states, in part:

“Unless expressly modified by court order or specifically granted to a guardian or conservator, all clients have: . . . the right to have access to his or her records, except as expressly limited by statute, and to have confidential treatment of all information in his or her records, including personal and medical records. Confidentiality does not preclude access to an individual's records by an individual or organization otherwise entitled under federal or state law to review records . . .”

In the DD Waiver system, this right is put to the test.

Individuals in the Waiver system have enormous amounts of paperwork regarding their lives which is distributed to large groups of people. These people may be family members, guardians, case managers, residential or day providers, therapists, medical professionals, state agencies, etc. Each of these parties has a function and a role requiring documentation for individuals they serve. This documentation may describe services, medical care, financial care, daily activities and decisions, toileting, bathing, if they become upset that day, etc.

The challenge for these supporting individuals who receive DD Waiver services is in protecting the privacy of the information which they possess for individuals they serve. While the information may need to be shared with others who support the individual, the determination of what to share and with whom can be a challenge. Later in this toolkit, there is a resource called “Who Else Needs to be Notified of Valuable Health Information?” which gives examples of what the various team members need to know regarding individuals they support. Sharing information in a “need to know” methodology is one safeguard for the privacy of who to share information with and what information is shared regarding individuals receiving services.

Also to be considered is where one shares information. Coincidental conversation or informal information sharing may be convenient but often violates basic privacy rules. Consider that the doctor communicates with his patient behind closed doors. Medical checkups occur behind closed doors. Medical procedures occur behind closed doors. Medical providers do not typically fax you your results. They call you in to share information with you or they mail the reports to you. And when you get to the appointment, they close the door.
In the DD Waiver system, however, we have often eliminated those doors when we discuss individuals we serve. Teams frequently have meetings where everything is discussed, even though only one or two team members need to know the information. A document with private health information may be faxed or mailed to upwards of ten individuals, and occasionally to a state office—sometimes there will be a fax cover sheet which states that the information is protected information but not always. Even when there is a fax cover sheet, though, the document may lay on a counter or shelf to be seen by anyone walking by without a second thought. We may have informal conversations at the front desk of an agency where there may be persons around who have no affiliation with the individual or who have no need to know the information being shared (an administrative staff typically does not need to know about an individual’s bowel schedule, for example).

It is our responsibility to eliminate these coincidental communications or accidental sharing of information. We can do this in several ways:

1. Consider who you are speaking with regarding individuals you serve.
2. Always consider if the person you are going to share information with has a “need to know” the information.
3. Share information in the most confidential manner possible.
4. Have meetings or conversations regarding individuals you serve in an office or conference room with a closed door.
5. If you must fax information regarding an individual or individuals, call the intended recipient and tell them that you are faxing it (thus minimizing the chance that the information will sit on a shelf for anyone to see).
6. Close the door to any room you are in prior to starting a conversation or phone call regarding individuals you serve.

Finally, it is important to realize that individuals we support have many people in their lives. There is frequent turnover in direct care staff. Case managers may move on to other things. When a person stops providing services to an individual, he/she no longer has the "need to know" personal medical information. Every effort must be made to maintain constant awareness of appropriate sharing of personal information. In these cases, it is your responsibility to assure that the individual is comfortable sharing information regarding himself/herself prior to any communication.