

## *Sensitivity to Personal Privacy*

*“The right to be let alone is indeed the beginning of all freedom.”* — Justice William O. Douglas

Cultural norms play a huge role in influencing how personal space and privacy are defined. Different cultures have different reactions to crowds and physical closeness. In addition to cultural norms, we all have our individual preferences for what privacy means to us personally. Some people don't mind loudly talking on their mobile phones in crowded situations. Others prefer to be more discreet and hushed in such situations to maintain their privacy in a conversation.

To be respected as individuals, we each have our own unique ideas of what it means to have our personal privacy honoured. We feel enormously violated when people are not sensitive to or respectful of our personal privacy. People with intellectual and developmental disabilities share all the same rights to privacy as anyone else, yet often infringements on privacy occur when staff and others are not sensitive to a person's distinctive and individual privacy preferences. In addition, staff members and other supporters may not have taken full advantage of opportunities to regularly teach people about their rights to privacy (not just during a yearly rights review). People receiving services may not have adequate support to know that subtle intrusions on any of their rights should not be tolerated or endured; and they may not have advocacy or strong support to assert and advocate for themselves when disturbances to their rights occur.

### **Quality in Practice**

- Assume (in the absence of strong evidence to the contrary) that privacy is important to people and do everything possible to preserve and promote privacy.
- Privacy is a right and we have a responsibility to promote all rights, including privacy. All people should have an expectation of privacy across settings. That expectation may vary in degree depending on where you are (for example you would have a different expectation of privacy at a sporting event, or at the mall, then you would in your own home.)
- Educate people about the importance of respecting the privacy of others and in ways of ensuring and advocating for their own privacy needs to be respected.
- Spend extra time getting to know what is most important to a person regarding individual privacy in these areas: grooming, dressing, receiving correction, talking about personal feelings, getting away from uncomfortable situations, seeing a doctor or lawyer, visiting with family or friends, and when feeling angry or upset.
- When it comes to privacy matters, accept “informed decisions” from a person as well as “informed refusal”.

### **Some Questions to Ask:**

- Who makes the decisions about the person's privacy?
  - Closing the door to the bathroom
  - Phone calls
  - Mail
  - Internet
- Who helps with personal care?
- How do we learn from people about their decisions regarding important issues about privacy?
- How do we support people when their personal decisions do not fit with what we perceive as the cultural norm or values of the community?
- How do we support people when we don't fully understand how important privacy is to the person?