

FIG 17-3 Information sessions should take place in a private, comfortable setting free of distractions and interruptions.

Parents should receive the kind of information they desire. This can be assessed by asking questions, such as "Do you prefer to hear detailed information?" Parents or other family members may have different preferences regarding the amount of information that they wish to hear. Most parents want a clear, simple explanation of the diagnosis; a prediction of possible futures for the child; advice on what to do next; an opportunity to ask questions; a warm, sympathetic listener; and, most important, time. Understanding of explanations is elicited with questions, such as "Do you see what I mean?" or "Is this clear to you?" Technical terms are used with simple definitions. If the parents are unaware of the term, they are given written literature or at least a written summary of the diagnosis.

Finally, the informing conference does not end with the presentation of devastating news. Instead, the child's strengths, appealing behaviors, and potential for development are stressed, as are available rehabilitation efforts or treatments. Parents can be encouraged to view their experiences as a series of challenges that they are capable of handling, particularly with available professional feedback. The parents are assured that the nurse will be available to answer questions and to provide further assistance as needed.

The preceding discussion relates primarily to the initial informing interview. However, because of the need for long-term follow-up, it is only one in a series of continuing discussions. In all