

11/16/2010

Let's call what we are planning "observing and participating in a free wheeling conversation about the use of the internet" among parents of at least one child diagnosed with autism. Let's try not to use the phrase "focus group" since what we are doing is so far from strict focus group standards (did any of our group get trained in focus group theory?).

So, we tell the parents that we are interested in observing them talking about their use of the internet as it relates to the diagnosis, treatment and education of their child. If they ask what we mean by this (and we should try to record that as well), we say (and this is an outline of the conversation guide we keep for ourselves) that we are interested in their use of

1. The "internet," by which we mean
  - a. E-mail
  - b. Search engines
  - c. Social network software (Facebook., etc.)
  - d. Etc.
2. For
  - a. Learning about autism
    - i. As the condition of a child
    - ii. And the resources available for treatment and other forms of help
    - iii. And the limitations placed on their personal lives or on their access to the resources
  - b. Disseminating their own knowledge or experience (teaching)
  - c. Networking with other families
    - i. Local ones
    - ii. Families they have never met except on line
  - d. Communicating with
    - i. The people who treat their children
    - ii. Organizations
    - iii. Institutions
    - iv. The legal system

Obviously, the items under 2. are a summary of Juliette's research plan. Our goal in this conversations is not to get specific answers to what are not strictly speaking "questions" but rather a reflection of what, at this point, we believe there is to know. Our quest is more for what there is to know that we do not know needs to be known or, more specifically, the manner of the knowing, and, even more specifically, the manner of the discovery that it is to be known, and the ethno-methods for getting it known.

So we look for stories, interpretations, disagreements and, if we are lucky, moments of instruction about autism when some parents tell some other parents what to do. If we can engineer this, unobtrusively, it ought to be good.