

Helping staff support choice

Michael W. Smull

As more and more people with significant disabilities are moving from group homes to supported living the challenges in supporting them in their choices increase. The staff involved with these individuals are often told to simultaneously support choice, build community relationships (and acceptance) and assure health and safety. Staff blessed with uncommon sense understand how to achieve this balance instinctively. However, many other staff members solve the perceived dilemma by only hearing the first or the last part of the message. They either support choice regardless of consequences or overly restrict people, in the name of health or safety. The middle part of the message, building community, gets lost in the struggle between choice and concerns over health and safety. What staff (and managers) often miss is that this is a balance, a balance that needs to be defined with each person supported.

In searching for ways to help people understand how to achieve a balance in supporting people I came across Charles Handy's "doughnut" principle (see figure 1). As adapted for use in supporting people with developmental disabilities it suggests that there are three areas of responsibility that we can define with each person we support. The at the center of the doughnut are the core responsibilities, those things that we expect staff to do without fail. These "core responsibilities" are typically a mix of issues of health or safety and those things that are most important to the person supported. The ring just outside of the core represents those areas where we expect staff to use judgment and creativity. They may continue to include issues of health and safety but they are in areas where staff are expected to try new ideas and not be punished if the ideas do not work. Outside of the doughnut are those areas that are not our responsibility, that are none of our business.

Inside a Person's Life

NOT OUR "PAID" RESPONSIBILITY
(THE DOMAIN OF FRIENDS)

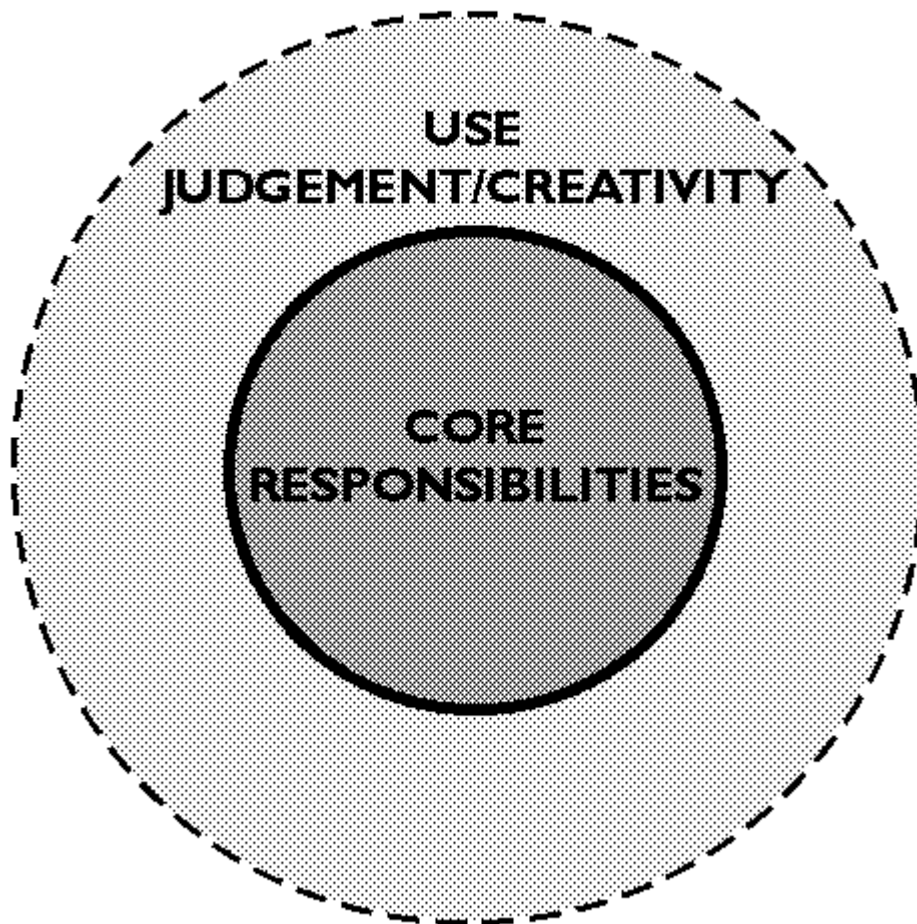


FIGURE 1

MICHAEL W. SMULL
(FROM CHARLES HANDY)

The boundary between core responsibilities and areas where people are to use judgment should be a sharp and clear. If this conceptual framework is to be helpful, sufficient time must be taken with staff to be certain that each person understands what responsibilities are within the core and which are in the area of requiring judgment. On the other side, the boundary between what is and is not our business, is deliberately kept "fuzzy". For example, what someone wears might be "none of our business" on a day to day basis but should fall into the area of "use judgment and creativity" when something inappropriate is being worn for a job interview.

The content of each area within and outside of the doughnut varies widely from person to person. Two people who illustrate how this works are Jon and Elizabeth. Jon lives in his own apartment in a Benicia, California. Jon is a man with a great imagination who is also an eloquent presenter. He has found that traditional disability system employment programs (workshops, enclaves, and work crews) do not work for him and is trying to build a career as a speaker and consultant. Jon also has Prader-Willi syndrome and much of his support revolves around helping him maintain the independent life that he loves while staying within his very limited diet. Some examples of the 3 areas of staff responsibility inside Jon's life are shown in figure 2.

Examples from:
Inside Jon's Life

NOT OUR "PAID" RESPONSIBILITY

- What I spend my money on--if it isn't food, it's my business.
- Don't interfere with or criticize how I choose to leave my room (if it isn't a health or safety hazard).

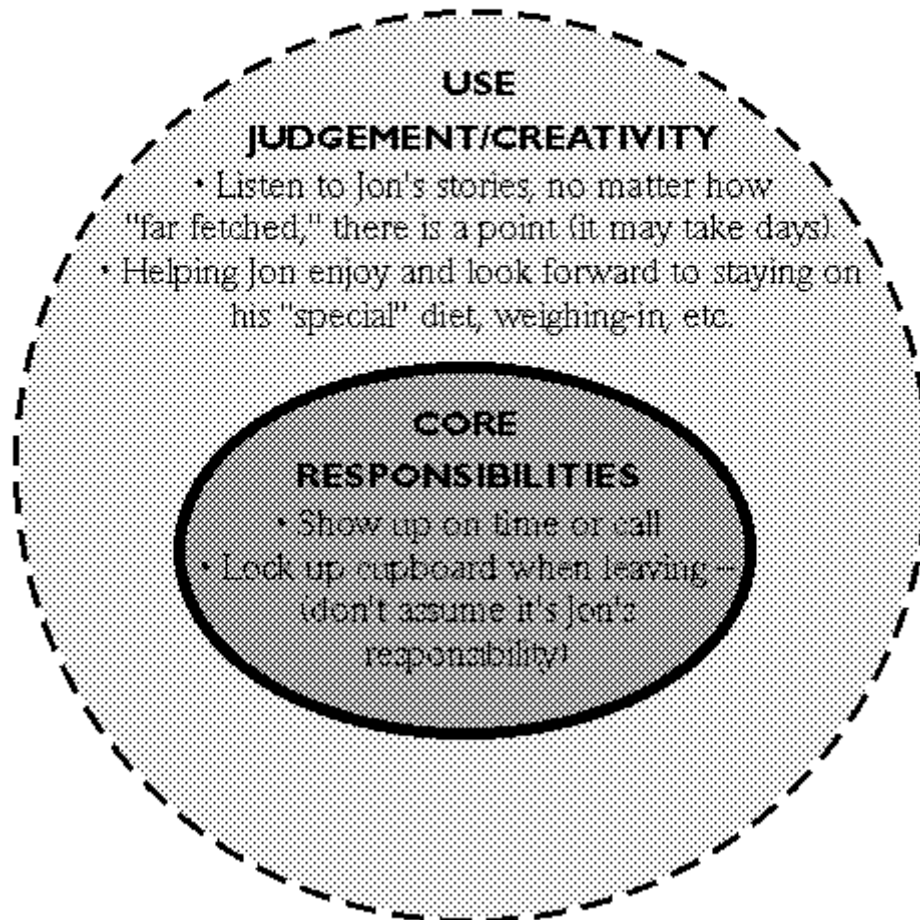


FIGURE 2

Elizabeth is a woman who one friend described as a busy lady who wants to busier. People who met her during her recent presentations to the Presidents Committee on Mental Retardation and at TASH in New Orleans have commented on her charm and wit. Those who have taken the time to talk with her have realized how much we have to learn from what Elizabeth has to say. As this is being written, she is living with her family but this will change as soon as she can recruit a qualified paid roommate. Because Elizabeth communicates by pointing slowly to words it is easy to not listen to how she wants to be assisted and Elizabeth needs a great deal of personal assistance. She relies on others for most of her personal care and eats using a G-tube. On the other hand she gets around quite well in her power chair and doesn't need anyone with her when she is off visiting during a conference. It will be critical for Elizabeth's life that staff understand their three areas of responsibility, some examples of which are shown in figure 3.

Examples from:
Inside Elizabeth's Life

NOT OUR "PAID" RESPONSIBILITY

- Don't interfere with the private time I spend with my friends. I don't need an interpreter, they are my friends and we communicate.
- Don't interfere with how I choose to handle the love interests in my life. I will ask for any advice I want and from whom I want.

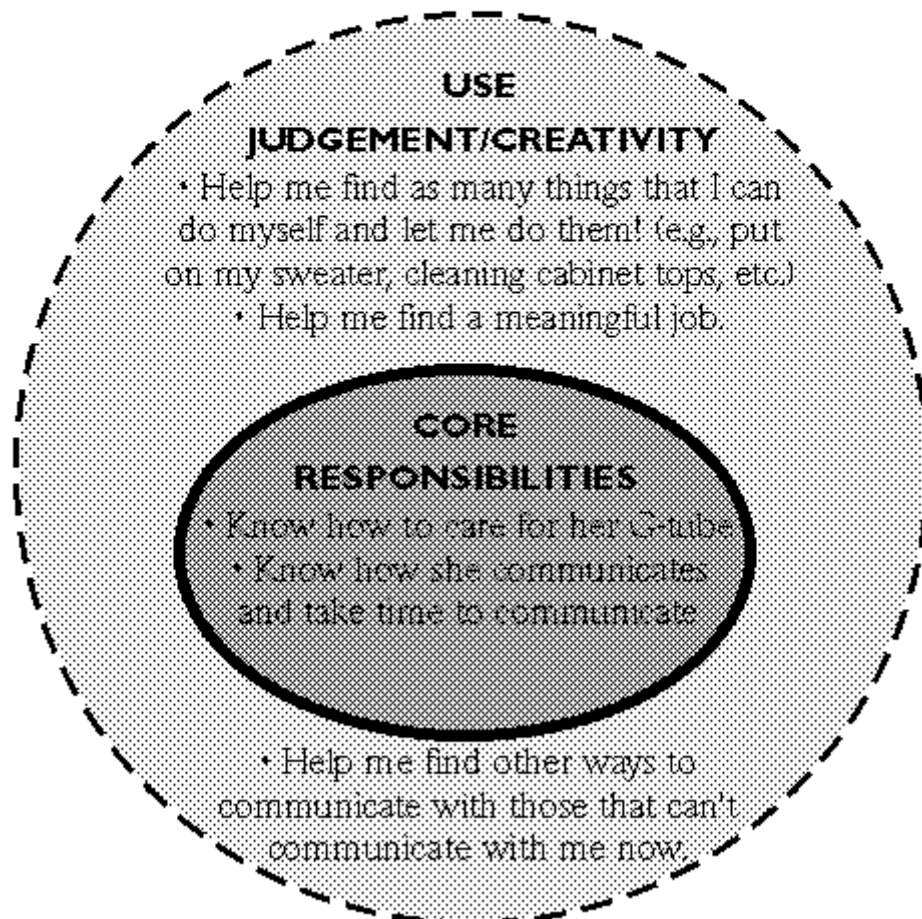


FIGURE 3

In the not too distant past we were quite comfortable in deciding where people with disabilities should live, who they should live with and how they should spend their time. Now we are trying to help people direct their own lives. We plan with people rather than for them and struggle to support the choices of each person. When we are careful and successful we help each person find the balance in their lives. A balance that reflects what people want, the resources available to them, and any issues of health or safety. Not surprisingly one of the lessons that we are

learning is that we need to help staff find the same balance in the support they provide. This adaptation of Handy's "doughnut principle" provides a structure to help staff find that balance with each person they support.

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