

**Testimony of Susan Stoddard, Ph.D., FAICP, InfoUse**

**ICDR Hearing, San Francisco, July 20, 2004**

Thank you for taking the time to hear from the field on research needs in disability and rehabilitation research. I am Susan Stoddard, President of InfoUse in Berkeley. My comments are based on many years of research and evaluation of employment programs for people with disabilities, the contributions of independent living centers, and opportunities for reducing barriers at home, at work, and in the community. I call two research needs to your attention today: the need for **personal assistance services in the workplace**, and the need for development of **land use planning** practice which reduces or eliminates current barriers.

**Personal assistance services** are one of the most essential services for independent living of people with disabilities. The American Community Survey 2002 shows that approximately 600,000 people of working age who have a self-care difficulty are employed, over 100,000 more are in the labor force but not employed, and almost 2.5 million (over 3/4 of those of working age with self-care difficulties) are not in the labor force at all. To what extent could this change with available PAS at work? InfoUse is a partner in the RTC on personal assistance services, with responsibility for workplace personal assistance services. Our formative work in our Center, where we have interviewed employers, disability employment specialists, and PAS users, indicates that personal assistance services is a new concept in the workplace, some states are beginning to encourage this concept, and personal care is rarely provided by employers. Services are beginning to be developed, but a number of important questions are not addressed at the national or the state level. We encourage an expansion of

NIDRR investment in this evolving concept and service area, to expand opportunity for employment.

- How many people with disabilities would be able to enter the workforce if PAS were available at work?
- What are the needs for workplace PAS for groups with traditionally low employment rates, (for example, people with severe mental illness)?
- What kinds of PAS are needed? The ADA addressed responsibilities for task-related services but not personal care services. To what extent are personal care services available in the workplace?
- What are the estimated costs and benefits of providing PAS at work?
- What changes in the PAS labor force will be needed to meet the needs for PAS at work?

**Land Use.** The second area I want to encourage is less developed in NIDRR's current menu of research topics: the relationship of **land use planning practice** and the expansion of community participation and access of people with disabilities. With the US Census 2000 and the American Community Survey, we now have disability measures available at the small geographical unit level. For the first time, local planners now have disability available as a local demographic descriptor. InfoUse is developing data templates for local planning as part of the RTC on the Demographics of Disability. I anticipate increasing awareness among planners, as community plans are developed. This is an opportunity for development of better information about how local land use and transportation decisions affect people's abilities to get around and participate fully in the community; it addresses a major determinant of environmental barriers in studying our government choices of where our land uses are

located, and how they relate. While the “universal design” concept focuses on architectural features and accessibility of specific buildings and structures; a land use concept focuses on the relationship of commercial and residential land uses, densities, relationship to automobile and public transit options, and other large-scale land use decisions which shape the built environment and the way we live and work. There is an emerging body of research which relates our land uses to our public health, with empirical evidence that low density suburbs contribute to risk factors for disabling conditions. We need additional research that relates our land uses to full participation for people with disabilities.

- What residential land use standards work best for all people including people with disabilities?
- What patterns of transportation and development density work best?
- How does existing land use pattern relate to where people with disabilities live?
- What planning tools are needed to support development of housing and services needed by people with disabilities?
- How do existing land use patterns relate to ability to work, go to school, or do other day to day activities? What is the impact of different land use alternatives for people with disabilities?
- Given more available disability data for local planning, how are plans influenced or changed?

These two areas address real barriers to full participation and advances are needed in both.

Susan Stoddard, Ph.D., FAICP

**President, InfoUse and Project Director, Workplace PAS, PASCenter**

**2560 9<sup>th</sup> Street #216**

**Berkeley California 94710**

**510-549-6520**

**[sstoddard@infouse.com](mailto:sstoddard@infouse.com)**