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New Jersey Systems Transformation: Focus Group Report

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RUTGERS

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Executive Summary

In this report, we describe results from ten focus groups held around the state of New Jersey to find out about how people search for information on long-term care supports and services. There were 97 participants, including caregivers, older adults, people with physical disabilities, and people with developmental disabilities, their caregivers or service providers. ***The primary finding of the groups is that people need help laying out a roadmap of the long-term care system and their place in it—they do not know what questions to ask in the beginning, and feel there is little help available to orient people to the system of services that exists.*** The people we spoke with generally found their best information through connections with people in similar situations—connections were made through formal organizations and informal groups.

We describe the successful search strategies employed by participants (including word of mouth information, health care providers, Google searches, government offices, community locations and the media). We also describe unsuccessful search experiences reported by participants (including confusion created by complicated programs, gatekeepers who gave incorrect or incomplete information, fragmented advice, phone menu frustration, language or other communication barriers, problems with the digital divide, and lack of services to meet their needs).

We distill some possibilities for state action based on the comments we heard, including discussions of how to:

- Ensure the integrity of information provided by state employees or contractors
- Present information in multiple ways to address the variety of ways people access information
- Empower consumers and caregivers to shape programs and services

Finally, we include detailed descriptions of the individual groups and of our methods so that readers can evaluate the evidence and draw their own conclusions.

Abbreviations

AAA – Area Agency on Aging

ADL – Activities of Daily Living

ADRC – Aging and Disability Resource Center

CIL – Center for Independent Living

CRPS – Complex Regional Pain Syndrome (see also RSD)

DDD – Division of Developmental Disabilities (under DHS)

DDS – Division of Disability Services (under DHS)

DHS – Department of Human Services

DHSS – Department of Health and Senior Services

DVR – Department of Vocational Rehabilitation

ED – Executive Director

MS – Multiple Sclerosis

NJEASE – New Jersey Easy Access Single Entry

PAAD – Pharmaceutical Assistance to the Aged and Disabled

SSD – Social Security Disability

SSI – Supplemental Security Income

RSD – Reflex Sympathetic Dystrophy

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Introduction

This report discusses the findings from ten focus groups held around the state of New Jersey with consumers or potential consumers of long-term care services and their caregivers. Groups were designed to have representation from older adults, persons with physical disabilities, and persons with developmental disabilities in the northern, central and southern regions of the state. We held three groups representing each population in each region of the state, plus a group made up of members of a caregivers coalition, which was in the northern region of the state. In all, we had 97 participants in the groups and incorporated comments from an additional 11 in our findings.¹ See Table 1 on page 29 for a detailed demographic picture of participants.

An Overriding Theme – “We Need a Roadmap!”²

The Ideal System

Regardless of their personal situation, consumers of long-term care services and their caregivers face similar situations and desire the same things. Often overwhelmed with the diagnosis of a chronic health condition, they don’t know what kinds of services exist or what questions to ask. They want to talk with a person knowledgeable about the existing system of services and supports who can look at their whole picture, help them determine what further information they need, and counsel them about their options so that they can make informed decisions about the selection of services.

The Reality

Consumers and their caregivers interface with the medical system, which may or may not be helpful, and does not provide all of the information they need. They receive a patchwork of partial information from the medical system and their social network which leads to hours spent navigating phone menus and other such actions, ferreting through haystacks of information to find the few needles that apply to their situation. They receive contradictory information. They are frustrated. The consumers and caregivers we spoke with are generally tenacious and outgoing enough to persist in the face of frustration. They generally find a social network of similar others with whom to share information. Even as their level of sophistication increases, they still face the patchwork of information—finding out about a program that did exist but doesn’t now, or one that would have been helpful had they known about it earlier. They often feel as though they and others like them are continually reinventing the wheel.

They are willing to do so, given the consequences of giving up, but they wonder about those who are less tenacious or less privileged, and they believe there must be a better way.

<p>Example 1: I have to know more than the person I'm calling!</p>	<p>Example 2: I'm burned out from the time this takes!</p>
<p>Participant 1: <i>"You almost need to be more educated than the person you're calling"</i></p> <p>Others: <i>"Yes!"</i> and <i>"True!"</i></p> <p>Participant 2: <i>"Then you have the right questions to ask"</i></p> <p>Participant 3: <i>"That's a big thing, you have to know what to ask"</i></p>	<p><i>"it was a full time job for me to do ... I am burned out. I have not used three quarters of my budget for Real Life Choices because I am burned out trying to find those resources, good resources that are acceptable—you get one answer here, another answer there—it's all day on the phone trying to straighten the direction out and I keep thinking, if I feel this way, what do the other people who don't have the energy ... the time, and the wherewithal to keep it all together ... You do not know what questions to ask when you make that first phone call, and nobody on the other end is helping you pass that."</i></p>

The Challenge

Getting from the existing reality to the ideal system will require designing an effective way of efficiently matching information and available services to relevant populations, freeing consumers, caregivers, and information and referral workers from continually reinventing the wheel. The state is already thinking about these issues in designing its Aging and Disability Resource Center (ADRC), and there is existing infrastructure to utilize in terms of bricks and mortar community agencies and phone personnel. Technologies such as email and the internet offer possibilities for improving the quality of available information and reaching growing numbers of users.

Structure of Report

This report will present the overall themes that emerged across groups and then discuss the specific populations. Finally, we will describe our research methods and provide details about each group so that the reader can get a sense of the individual discussions.

We have organized our presentation of the overall themes in several sections. First, a participant context section will give a flavor for the kinds of participants contributing to the themes discussed. Next are three sections—possibilities for state action, successful search strategies and unsuccessful search experiences. Possibilities for state action presents the practical implications of participants' experiences by summarizing what participants thought

the state could or should do to improve the flow of information to them. Successful search strategies discusses the ways in which participants found or thought they would find needed information about long-term supports and services. Finally, unsuccessful search experiences describes the various frustrations and barriers that participants found in their search experiences.

Participant Context

Regardless of the kind of chronic health problem involved, it is scary, overwhelming, expensive, disorganizing and generally upsetting for the people dealing with a condition requiring long-term care services. Consumers and caregivers have their lives turned upside down (and inside out) at the onset of the condition or the birth of a child with chronic health needs, and struggle to keep going afterward. This makes communicating with this population more challenging than with the population in general. We talked with consumers and caregivers of all income levels in the North, South and Central regions of the state. Some lived in very densely populated areas and others in sparsely populated areas. Our groups included African American, Latino, Asian-American and white participants ranging in age from the early 20s to the early 90s. Some were older adults contemplating but not yet needing long-term care services. Consumers had a variety of physical or cognitive disabilities and required varying levels of assistance. Some relied on family members while others employed aides. Some used wheelchairs or other assistive devices. Some of the individuals with cognitive disabilities we spoke with were residents of a developmental center who were contemplating transition to the community; others had successfully transitioned. We talked with more women than men overall, although 23 of our participants were men. See Table 1 on page 29 for a detailed demographic breakdown of participants.

Possibilities for State Action

We wanted to present early on the practical implications of our participants' experiences. In this section, we outline potential actions that could be taken to address some of the negative experiences reported by group participants. In most cases these suggestions were made by participants directly; in a few cases, this represents our interpretation of what could have made participants' experience more positive.

Ensure integrity of information

Many of our participants, including service providers, had trouble getting correct information. With programs and eligibility standards subject to change, everyone needs a trusted source of information that will be kept up to date. The internet is an ideal resource for this. The www.njhelps.org site is a good resource (assuming it is kept up to date).³ In addition to designing and updating information, the state could prevent misinformation by informing gatekeepers and enforcing accountability for providing correct information in the following ways:

- Employees should have easy access to program details and to resources to answer questions they may have
- Employees should give their full name or a unique number that will identify them
- Employees should be trained and periodically monitored to ensure that they are providing correct information

Present information in multiple ways

There is no one-size-fits-all approach to presenting information. Our groups showed a digital divide between those comfortable with the internet and using the search engine Google to find most of their information and those who preferred to get information over the phone or in printed form. Accessibility considerations are important when information is presented—for those with limitations in vision, hearing, literacy or language.⁴ Some suggestions from participants were to:

Provide comprehensive web sites

For the web-savvy, having comprehensive information available on the internet would satisfy their desire for information and keep in-person resources available for others. This population could potentially utilize information designed for providers.

Have in-person consultation available

In addition to well-designed and comprehensive web sites for the tech-savvy, have a knowledgeable person available to discuss issues with people, easily reachable in person or with consumer-friendly phone menu principles⁵

- Counselors don't have to know everything, but should know where to refer and follow up—like a generalist case manager
- Much infrastructure exists already—there are Area Agencies on Aging (AAAs) and Offices on Disability in every county, the NJEASE⁶ number and the New Jersey Department of Disability Services (DDS) toll free I&R number. Also, many towns have senior centers, many of which have social workers on hand.

Make smart use of personal information

Many participants in all types of groups thought that the state should allow people to opt in to get information about programs relevant to their circumstances or target mailings to people with known disabilities or conditions. People see the extent to which businesses are able to target information to consumers and ask why the state cannot do the same, particularly when they have given personal information to the government to apply for various programs. Suggestions for finding appropriate populations included:

- Senior housing complexes
- Town property records often indicate senior citizen status
- Contact information for people receiving government benefits
- Contact information for people on Division of Developmental Disability (DDD) lists

Provide explanation-rich resource directories

Many resource directories are a list of phone numbers without any description, leaving a lot of leg work to users. Any description that space allows can help save people precious time in making phone calls. The comprehensive resource directory put out by the Department of Disability Services⁷ often contains descriptions and explanations as well as numbers. We received two comments on this particular directory—one from a novice user who found it overwhelming; another from a sophisticated user (who worked for a county office on disability) who found it a very useful reference tool. Several people in our Camden County group liked a resource manual put out by the county that provides explanations as well as contacts.⁸ Finally, a manual put out by the Morris County Caregivers Coalition attempts to provide a roadmap for caregivers of what kinds of services exist, but refers them to local resources for up to date information.⁹

Consider methods to empower consumers and caregivers

The consumers and caregivers we spoke with were undoubtedly above average in their willingness to participate and advocate for themselves. We were impressed with their determination and passion, yet at times struck by what seemed to be a lack of understanding about how government works, which may prevent people from being as effective as they could be in advocating for themselves.¹⁰ The three agencies collaborating on this grant cannot provide the civics education that many argue is lacking,¹¹ but can take some steps to facilitate the knowledge and connections that people need to be able to effectively advocate for themselves or those they care for.

Transparency in operations

Part of providing good information is being transparent about program operations so that consumers or caregivers can 1) effectively share information amongst themselves and 2) know how to target complaints. Transparency includes such items as how much funding is allocated to agencies and programs and where funds come from, who is eligible for programs, how program processes work (including how applicants are prioritized should applicants exceed resources), how many people are served by programs, and how many applicants there have been. Focus group participants (consumers, caregivers, and service providers) complained widely about lack of transparency in program operations.

Encourage information sharing

All our groups found their best information through social networks, particularly from others facing similar situations. Anything the state can do to encourage such connections would be helpful. The resource directory put out by the Department of Disability Services¹² contains contact information for a variety of groups based on conditions—this is a good start. One of our groups for people with Developmental Disabilities or their caregivers or service providers thought that the Family Support Councils provided a potential for information sharing and advocacy as well (though not as currently operating).

Harnessing complaints effectively

Consumers do not always know where to make a complaint and may waste their own time and that of agency staff when directing complaints to staff lacking the authority to address them. For example, complaints are often about issues above the level of agency staff, such as an inadequate absolute level of resources for services as opposed to a particular program that isn't running well. To be effective, this type of complaint needs to be directed toward increasing agency budgets instead of toward staff tasked with managing within an existing budget. There are two main ways of dealing with such complaints:

- External: Refer consumers to advocacy groups
- Internal: Seat a commission to hear and process complaints

Successful Search Strategies

We heard many similar stories from the different types of groups about their successful search experiences.

Word of mouth through social networks, including community organizations

Word of mouth was frequently mentioned in our groups as well as previous focus groups held for the New Jersey ADRC. The sources for word of mouth information included:

- Condition specific organizations
- Support groups
- Community groups
- Friends, family, coworkers

Health care providers

Many participants mentioned health care providers—doctors or other health service personnel as well as social workers employed by hospitals or rehabilitation facilities—as a source of information. One participant had helped develop a brochure to be distributed to pediatricians and hospitals.¹³

Google

Many participants told us their main search strategy was using the search engine Google to search the internet. Businesses often pay consultants for search engine optimization to make sure consumers can find them in this way. Google provides helpful information on this topic freely to webmasters.¹⁴

Government offices

Participants mentioned government offices at all levels as helpful (and unhelpful)—state agencies, county boards of social services and offices on disability, and municipal senior centers or other departments. This includes resources designed by government offices and talking with staff. Agencies or counties put out resource guides that people found effective (Camden and Bergen counties were mentioned, as was the New Jersey Department of Human Services).^{7,8,24}

Community locations

Several participants mentioned finding information somewhat serendipitously in their communities—just by walking around, or from fliers posted in apartment complexes.

Media

Among media sources, newspapers were mentioned most frequently as a source of information—both larger regional newspapers and local newspapers (see detailed reports for specifics). Radio and television were suggested as outlets for publicity when we asked participants for their ideas, but they generally did not report getting information on services there (there were some reports of learning useful information about medical conditions from these sources, however). One state agency has put together a list of media outlets for the affirmative marketing of affordable housing that could be used as a resource.¹⁵

Unsuccessful Search Experiences

Cumbersome search process

Every consumer or caregiver has to ferret through haystacks of superficial information to find the few needles that apply to their situation. One caregiver described having to make twenty phone calls over several days, repeating the situation each time, to get the information she needed. Parents of children with developmental disabilities often found out about programs that would only have been useful had they learned of them earlier, when their children were younger.

Incorrect or misleading information

There were two main sources of incorrect or misleading information.

Misinformed gatekeepers

This was reported most frequently by parents of children with developmental disabilities, who reported that DDD caseworkers were an unreliable source of information. Service providers also complained about inadequate or conflicting information from DDD. Inadequate or conflicting information was also reported in other groups, particularly when employees were trying to describe programs in another department.

Misleading marketing

Many of the populations we studied are potential markets for insurance, health care products or assistive technologies, or various “cures.” Several participants expressed a desire for help sorting out the truth of claims provided and distinguishing good actors from bad—particularly where government encourages people to take personal responsibility by purchasing from the private sector (for example, long-term care insurance).

Fragmentation and complicated eligibility for programs

Many people think of government as a single unit. In reality, government programs are fragmented—that is, administered by a variety of agencies whose staff may or may not know of similar programs in other agencies. In addition, eligibility for programs is often complicated in an attempt to target resources to the most needy individuals. This can result in confusion as to whether a person is eligible for services and delays in decisionmaking as the needed documentation is gathered and processed.

Several participants described problems due to complicated eligibility requirements—applications submitted that were lost somewhere down the line, and supporting documentation that had to be resubmitted multiple times (often these problems were compounded by problems getting a response from the agency as to the status of the application). As one participant who went back and forth several times with the PAAD program (Pharmaceutical Assistance for the Aged and Disabled) put it, *“I wasn’t rejected, I was procrastinated.... Last year they sent my application back four times. It asked for tax information that was already in there. I called them and asked them what I could do to remedy the situation. I did exactly what they said and they still sent it back. I think they are trying to get people to not be on that system because they do not want to give away money.”* This participant also had problems getting through to the program’s toll free number and, prior to the back and forth, had not received her reapplication materials from the agency.

There was also confusion due to the fragmented nature of programs. For example, PAAD and the Senior Gold programs are available for younger disabled people as well as seniors, but are administered by the Division of Senior Benefits and not mentioned on the Department of Human Services (DHS) website with other programs targeting younger disabled people (the www.njhelps.com tool does include them, however). Also, the name “Senior Gold” is misleading.

Lack of holistic information or advice

A person newly diagnosed with a chronic disability (or his/her caregiver) generally does not know what kinds of services are available or what kinds of questions to ask. Each person may need a slightly different package of services depending upon their needs and resources. Our participants described trouble conducting their searches because they did not know what to ask and often found that information and referral personnel did not help them to do an inventory of their existing needs and resources to identify what they really needed.

Sometimes in the rush to solve one need, the potential consequences of a given solution were not explored. For example, to solve his transportation problems, one of our participants (who had a spinal cord injury incurred in adulthood) bought an expensive van modified for his disability. He wound up not using the van, and hadn’t realized that he’d never be able to sell it because of the modifications, so he is stuck making payments on it. He wondered why no one had warned him of the difficulty he would have in selling the vehicle—as a newly disabled person, he was accustomed to the concept of a robust used vehicle market and was not aware of the limited marketability of modified vehicles.

I want a person to talk to!

Everyone hates phone menus when they seem designed to avoid letting people talk to a person. For routine transactions, they can be useful, but when the situation does not fit any of the options and there seems to be no way to communicate, it raises callers' blood pressure. There are some standards for how to arrange phone menus to be customer friendly.¹⁶

Language or other communication barriers

Those who did not speak English well were at a severe disadvantage in looking for information. They had trouble interacting with providers and were often simply hung up on when calling for information. Much information on the internet is only available in English—even where there are brochures in Spanish, sites often say “Brochure English Title (Spanish)” which may not be recognized by Spanish speakers.

Those with visual disabilities are also at a disadvantage—several participants noted that web sites are often unfriendly to those with visual disabilities¹⁷, and one of our participants pointed out that public notification requirements for housing opportunities often involve only newspaper ads, which those with visual disabilities will not be able to see.¹⁸

Digital divide

Some consumers are very internet savvy and have no trouble at all finding information. For these consumers, ensuring that programs appear with a Google search and providing comprehensive information on the web in an accessible format would be helpful. Others are not using the internet and prefer printed resource directories or someone to help navigate information. Here is an exchange from one of our groups showing the disagreement among different types of consumers:

Participant 1- The way to get information is just one word, Google... The problem is getting the services that Google takes you to... Getting information is not the problem. I don't care how many websites the state sets up, or how centralized or decentralized... Getting services is the problem.

Participant 2 – There are some people that are not as savvy.... I made a list of all these things and some people who were pretty smart people didn't know about these things. Not everyone is going to find out this information because they are overwhelmed. [She mentions a variety of programs with different eligibility criteria and concludes that while you could find out each of them individually by googling, it would be easier to have someone identify programs based on your needs.] However, she notes: Nobody knows about these things all together.

Participant 3 – I agree, it's frustrating when you know your need, calling around. You hear, call this place... then, oh no, they gave you wrong information, call this place. I give up. No patience to make phone calls and phone calls and phone calls. As a matter of googling... If there was some kind of roadmap, if you have an issue with this, go here.

Participant 2 – I think a lot of people give up. Don't want to go through the haze of all these agencies or waiting two hours to get into 800 numbers for the state. If you call PAAD, you never get to speak to a person, just voicemail. There is nothing that says if you need to speak to a person, push this button. All questions can't be answered by voicemail!

Participant 4 – I am not savvy enough to google and find information and I'm sure other people are not either. The state has the information of who has a disability. Can't the state mail roadmap once a year in hard copy. This is your problem, this is the qualification needed. Write down what qualifications so that the receiving facilities don't get phone calls from people who are not qualified. Give us the information so that we would only call if we are qualified.

Inadequate services

Though several participants expressed gratitude for existing services, it was clear that existing services do not meet current needs and can be frustrating to use, which can erode the willingness to look for other services. One example is transportation, which is a major problem for people with limited mobility, who find it difficult to arrange private transportation formally or informally due to the problems involved in getting into or out of vehicles. Those with Medicaid can get transportation to medical appointments only. The Americans with Disabilities Act requires alternate transportation for those within one-half of a mile to public transportation if they are unable to access public transportation (New Jersey expands this to three-quarters of a mile).¹⁹ When this alternate transportation works out well, it can be very useful. However, there is a long pickup window of 40 minutes duration—in a worst case scenario, the person with a disability is out at the curb waiting for 40 minutes in bad weather. It is also a shared ride service and thus not necessarily a direct ride to the person's destination (one participant described an hour-long ride to go two blocks, due to circuitous routing).

Can't you find me?

Consumers noted that they had to provide a lot of information about themselves to apply for various programs and wondered why this information couldn't be used to let them know about programs or services for which they might be eligible. Some thought the state should mail out information; others just wanted the opportunity to sign up for emails about programs on certain topics. As one participant succinctly noted: *"we need more outreach ... whoever they are, they know who we are and we should be getting contacted by them."*

Subgroup Characteristics and Themes

While there were common themes across all groups, there were also themes common to the subgroups of consumers or caregivers we spoke with. For details on the groups making up the subgroups, see the Detailed Reports section.

Caregivers

Participants

Though we had only one group specifically designated as a caregiver group, we spoke with at least 26 caregivers as most of the participants in two of our groups focusing on people with developmental disabilities were caregivers of their children with developmental disabilities. Some participants in our older adult groups were caregivers as well, but we did not seek or track information on caregiver status in those groups. We had 13 participants in our Morris County Caregivers group, five parents of children with developmental disabilities in our Union City group, and eight parents of children with developmental disabilities in our Lawrenceville group. Caregivers were largely white women under age 65, although there were some participants outside these categories. Educational backgrounds and income levels were more varied. See Table 2 on page 30 for a more detailed listing of characteristics.²⁰

Themes

Caregivers were always faced with juggling multiple responsibilities. In addition to their caregiving responsibilities for their friend or family member with a chronic illness, they generally also had other caregiving responsibilities for other family members, employment or other responsibilities. Some were caregivers for someone who lived in a different community, which made it harder for them to learn about local resources. In our focus group that was exclusively caregivers, many had cared for several people at one time or several different people over time (a child with developmental disabilities and an elderly relative, for example). These multiple responsibilities meant that caregivers in particular needed help putting together a package of services to assist their friend or family member. They generally found this help from people in similar situations who had struggled to find similar information previously, or from institutions such as schools for disabled children where staff were familiar with programs. Sometimes they met similar families through schools or support groups.

Older Adults

Participants

We had 33 participants in our groups for older adults, held at senior centers in the three regions of the state. We held one group in a suburban part of Camden County with participants coming from the city of Camden as well as more sparsely populated areas. Our Hackensack group was composed solely of people who lived in that densely populated region. Our last group was held in East Brunswick, a suburban area in central Jersey. Twenty-seven of the participants were women and six were men. One group was exclusively female. Slightly less than half of participants were white. Most participants were between age sixty and age seventy-five (eight were older than 75 and 4 did not answer the survey question). Incomes were clustered at the lower end of the spectrum for those who answered the question (twenty participants reported making less than \$40,000 per year). Educational levels were quite mixed among the 24 participants who reported them—five participants had less than a high school

diploma and four had advanced college degrees, with the rest somewhere in between. See Table 3 on page 31 for a more detailed listing of characteristics.

Themes

Themes in our groups for older adults were frustration with phone menus and wanting a person to talk to. We also saw the digital divide here—this could have to do with age, income, or education, though none of these variables was determinative. We also heard a fear of being taken advantage of with respect to insurance products or health care treatments. Unlike our other groups, the older adults we spoke with were not generally using state funded services (other than programs at their senior center) and thus had fewer comments on their experiences finding services.

People under 60 with Physical Disabilities

Participants

We had 19 participants in our three groups of younger adults with physical disabilities. In North Jersey we talked with eight participants, most of whom had spinal cord injuries and one of whom had a visual disability. In Central Jersey we met with four people who had multiple sclerosis (MS). In South Jersey we attended a support group meeting for people with reflex sympathetic dystrophy (RSD), also known as complex regional pain syndrome (CRPS). More than half our participants were between 45 and 60 years of age (five were younger, one older and two did not report). Many did not report income or educational levels, but those who did tended to have fairly high levels (\$100,000 per year or more; college or more). These groups tended to be much more gender balanced than our other groups. See Table 4 on page 32 for a more detailed listing of characteristics.

Themes

A major theme in our groups of younger people with physical disabilities was the financial expense that came with the disability and how this was not considered with respect to determining program eligibility. People with disabilities often must pay out of pocket for supplies, transportation, medications and the like in much greater amounts than people without disabilities, and yet when evaluated for eligibility for help with utility expenses, for example, these differences are not taken into account. People felt this was unfair. They also felt vulnerable at times to misleading marketing that played up their hopes for alleviation of pain or other symptoms.

We saw the digital divide in these groups as well—in some cases it related to income, education or English language familiarity. Like other groups, people with physical disabilities tended to get a lot of information from organizations focused on certain conditions (web groups for those with spinal cord injuries, for example). The annual Abilities Expo also got several mentions. Also like other groups, people in this group expressed a preference to get information targeted to them.

Finally, this group experienced conflicted feelings about employment as it related to the loss of medical insurance or other benefits. Some felt that private insurance was superior to Medicaid, but this definitely depended on the quality of the private plan.

People with Developmental Disabilities

Participants

We had a wide variety of participants in our groups designed to record the experiences of people with developmental disabilities or their caregivers. In Vineland, our group at the Developmental Center included three consumers who had transitioned from the center to community settings, and two consumers who wished to make such a transition. It also included support staff from the center and the community settings, and a family member of one of the consumers. Our group in Central Jersey included family caregivers and service providers. Our North Jersey group was exclusively family caregivers (aside from the service provider host). In addition to the five consumers mentioned, we talked with 14 family members and 13 service providers. About half our participants were white, one quarter were black and 16 percent were Latino. Income and education were largely unreported, with reported incomes quite variable and education mostly college or advanced degrees. Only five of our 32 participants were men. See Table 5 on page 33 for a more detailed listing of characteristics.

Themes

Most of our conversations about searching for services for people with developmental disabilities were with caregivers or providers. As in other groups, caregivers found that personal networks with caregivers in similar situations led to the most helpful information. Both caregivers and providers reported receiving misinformation from DDD caseworkers, and expressed frustration at the waiting lists for community services. Caregivers felt that searching for and managing self-directed services was a full-time job, and that there had been a degradation of the support broker role to simply handing out phone numbers without the context that could save caregivers time in making phone calls. There was some disagreement about the distinction between empowering parents versus pushing work onto parents that agencies should be doing. There was a sense that caregivers were having to reinvent the wheel and needed a way to combine their efforts to save time and headaches. There was an often-expressed frustration at finding out about needed services too late. Many parents felt that agencies had their information and should do more outreach, and that schools, DDD and the Department of Vocational Rehabilitation (DVR) should do a better job of collaborating.

Detailed Reports

Caregivers—Morris County

We held one caregivers group on the evening of February 21, 2008 at United Way of Morris County in Cedar Knolls. Participants were recruited by the coordinator for the Caregiver

Advisory Panel.²¹ The coordinator attended, as did a United Way staff person and a staff member from the Department of Health and Senior Services. We had 13 participants—two men and 11 women. Participants' ages ranged from the late forties to the early sixties, and their annual incomes ranged from less than \$20,000 to more than \$100,000. Almost all participants were white. All had some education beyond high school. Many cared for more than one recipient, and all had been caregivers for at least two years (some for 30 or more years). The ages of care recipients ranged from children to older adults in their 90s and the conditions requiring care ranged from mental to physical (with several combining mental and physical conditions). Most in the group knew each other from previous meetings of the coalition. There were also five email and six paper responses from members who were unable to attend, which have been incorporated.

Discussion Points

- Caregivers are often responsible for more than one care recipient
- Caregivers spend enormous amounts of time searching for information
 - Often hard to find _relevant_ information—i.e., one woman could not get the number for her local Medicaid office, just general information about Medicaid
 - Many calls and several days to get needed information
- Services are inadequate—transportation a big issue, but also others
 - May not exist at all
 - Inadequate coverage (transportation with limited hours or pickup points)
 - Expensive for those not on Medicaid (esp. transportation)
- Programs and eligibility requirements are complicated and there is a lot of misinformation
 - E.g., state workers for one program may not understand other state programs
- People often don't know what services exist or what questions to ask and need help putting together a package of services—i.e., transportation, respite, school services
- Associations that dealt with large numbers of people with similar conditions were often helpful in gathering useful information and passing it on—schools, autism groups, Alzheimer's groups, UCP, Day Center support group etc.—including internet support groups
- Word of mouth was an important way that people found out about services (or activities like the coalition)—friends, family, other parents
- Coalition puts out resource guide:
<http://www.uwmorris.org/priorities/caregiveresource.html>
- DDD caseworkers overworked, not helpful—will confirm information if you know it but not tell you
 - Not allowed to email clients, hard to get through on phone
 - Need clear guidelines on DDD rights/responsibilities for parents for transparency and better proactive assessment by DVR for when kids get out of school
- Newspapers used—Star Ledger, Observer Tribune, local recorder paper in Mendham mentioned
- Community presentations, library, Day Center

- Senior TV Channel
- Call state agency
 - 20 calls and hours to get information they needed—had to repeat situation many times—suggest streamlining information and sharing so consumers don't have to repeat for different agencies
- Information from Health care provider (verbal, brochures)
- Internet sites not good for visually impaired

Suggestions for publicity

- Coalition
- Churches
- Direct mail (large print)—elderly and mentally ill often isolated
- Better information on websites (DDD just has very general)
- Quality information avail (like BBB for service groups)
- Recommend gatekeepers have better information
- Consider that caregivers may not live in same area as care recipient

Older Adults

We held three focus groups with older adults at several senior centers. Participants were recruited by center staff, who generally sat in with the group (we did not include staff in our participant count).

South Jersey – Camden County

We held a group in the morning of March 5, 2008 at the Camden County Senior Citizen Day Center in Blackwood. Center participants are bused in from various locations throughout the county, and had to give up the opportunity to go shopping in order to participate in the group. We had 11 participants--three men and eight women. Four were African-American and seven were white. Ages ranged from 62 to 91 (four were in their sixties, two in their seventies and five were over eighty). All had household income below \$40,000, and most were below \$20,000. Most were high school graduates with one indicating college. None drove themselves—about half used public transportation and the other half got rides from someone else. All but three lived alone; one lived with a spouse and two with their children. Most lived in apartments. None needed help with activities of daily living (ADLs), although there were some with impaired mobility and/or vision in the group. Most in the group knew one another from participation in day center activities.

Discussion Points

- Word of mouth was an important way of hearing about services (several revelations occurred within the course of this group, in fact). Sources included:
 - Other participants or staff in day center
 - Senior citizen apartment communities that have community rooms where residents can gather

- Churches
- Boro hall staff
- Police officers or fire personnel
- Community groups or clubs like an over 60 club in Mt. Ephraim
- Service workers who knew of other services (e.g., a van driver who gave a participant the number for the Medicaid office)
- County puts out helpful resource book that many participants used²²
- Participants had not heard of 211, but thought it was a good idea
- Other ways of hearing of services included local newspapers, including:
 - Golden Voice Newspaper²³
 - Courier Post (Cherry Hill)—a special insert, which the participant thought they didn't have any more, it was several years ago
- Participants were mixed on whether they thought newspapers were a good way to publicize things—many didn't read them and noted that some seniors have vision problems, etc., but that it may be good for family members or others who look for services for seniors (several participants mentioned that children or other relatives kept an eye out for relevant services).
- Some participants who had had rehabilitative services found them a good referral source for aides or other needed services. When referred by medical personnel, participants indicated that the personnel often made phone calls on their behalf rather than giving them a flyer.

Suggestions for publicity

- Have speaker come to day center
- Flyer or newsletter posted on bulletin boards
- Direct mail to those that towns know are seniors because of property tax records; residents of senior complexes

North Jersey – Hackensack

We held a group in the morning of March 12, 2008 at the Americas Unidas Multicultural Center in Hackensack. Center staff recruited participants—all women—from among center users. We had ten participants—two were white, one South Asian, two black and five Hispanic/Latino. Their ages ranged from 63 to 75, with a mix of high school and college graduates (and several not answering). Household income was also mixed, with several reporting below \$20,000, several in the \$20,000 to \$40,000 range and one in the \$60,000 to \$80,000 range. Three participants relied mostly on public transportation while the others drove. Seven lived in apartments or condos and three in single family homes. Six lived alone and four with a spouse. None required help with any ADLs, though one had a husband who needed some assistance (she was his primary caregiver). Most participants knew one another from center activities.

Discussion Points

- Sources of information
 - Word of mouth was an important way of hearing about services
 - Center staff or other participants
 - Friends, family, neighbors
 - Local newspaper
 - Bergen County 2007—county and municipal directory²⁴
 - Seniors Blue Book—A Seniors Resource Guide, Bergen and Passaic Counties (a free booklet on display at the center)—see <http://www.seniorsresourceguide.com/>, which links to <http://www.seniorsresourceguide.com/directories/Bergen-Passaic/index.html>; Guides are also in Somerset/Hunterdon and Union/Essex and they eventually plan statewide coverage; see http://www.seniorsresourceguide.com/network/newjersey_coalitions.html
 - Walking around (dense urban area)
 - Presentations at the Center
 - Written materials at Center
 - Doctor helped get family member on Supplemental Security Income (SSI) when he had a serious illness
 - Hospital social worker (mixed here—one person reported a good experience with a social worker; another participant reported a negative experience)
 - Public events
 - County event in park featuring written information people could take
- Barriers to information
 - Hard to get through to Medicaid
 - Phone menus when looking for information—can't talk to a person
 - Language—need translators
- Gender—several mentioned that their husbands did not want to join them at the Center. We saw a few men, but mostly women.
- Desires for information
 - Participants expressed a desire for information on long term care insurance and medicine (self care, disease, etc.) from an unbiased source
 - Concern that insurance companies might rip people off, go out of business, etc.
 - Concern that medical professionals may not be competent or willing to take enough time with consumers
 - Theme: wanted information on options
- Suggestions for effective presentations
 - Basic information presented in one hour with time for questions
 - Recognize that people may not want to ask questions in an identifiable way about financial/medical issues
 - Allow people to write questions on a notecard
- Policy suggestions

- Many participants were above the income/asset level where they could qualify for government programs and wondered what was available for them. Some felt that Medicare or Social Security should cover long-term care.

Suggestions for publicity

- Informational presentations at Center
- Churches
- Flyers in community locations
 - Stores
 - Housing complexes
- Hospitals
- Schools/universities
- TV/radio—targeted (e.g., Spanish language)
- Internet (for younger people)

Central Jersey – East Brunswick

We held a group in the afternoon of May 19, 2008 at the East Brunswick Senior Center. The meeting was publicized ahead of time in the Center’s newsletter and was also announced as it occurred for any last-minute attendees. We had twelve participants—three men and nine women. Two were South Asian, one was East Asian, eight were white and one did not answer and we were not sure of the person’s race/ethnicity. Four participants did not fill out our brief survey. Of those who did, ages ranged from 62 to 85, and most held college degrees. Household income was mixed, with two reporting below \$20,000, one reporting \$40,000 to \$60,000 and several reporting \$80,000 or more. Most participants drove themselves; two reported primarily riding in cars driven by others. Most lived in single family homes (two alone and several with spouses), and two lived with their children. None reported needing help with any ADLs. One participant had vision problems requiring assistance.

Discussion Points

- Several mentioned East Brunswick cable channel 3 (broadcast events)
- Several felt the local newspaper (Home News Tribune) was a good source
- In this municipality, the senior center and library were in the municipal complex, which made the center visible to the town
- Participants complained of poor information regarding insurance they had, and not having a way to ask questions about it (on hold for 30 minutes, frustrating phone menus, etc.)—this was for retirees on the state health insurance plan as well as those on Medicare and Medicaid.
- There was some discussion of the naming of programs or departments—one participant argued that names such as “Senior Center,” “Department of Aging,” “chronic disease” are a turnoff, and other participants agreed.
- Participants discussed direct and indirect ways of reaching the senior population

- Direct included AARP, County Dept on Aging, senior centers, elder law attorneys, insurance company representatives, health care providers and social workers (esp. at hospitals and including associations such as the hospital and physicians associations), meals on wheels
- Indirect methods included
 - outreach at health fairs, malls, schools (elementary through college as well as community “adult schools”—noncredit courses), beauty parlors,
 - information provided in newspapers, church bulletins, paycheck stuffers, inserts with utility bills, postings in bathrooms
- No one had heard of NJ211

Suggestions for publicity

- Need to use multiple methods of communication (see direct and indirect methods discussed above)
- Consider that seniors may not use computers
- Information should be clear, use large fonts, emphasis (where necessary) such as bold, and repeat important information.

People with Physical Disabilities

Central Jersey – Oakhurst

We held a group in the morning of June 9, 2008 at the Mid-Jersey Chapter of the National MS Society. The Director of Programs and Services recruited participants and participated in the group. Other participants included two men and two women, all of whom had MS. One of the participants phoned in as she was unable to attend in person. Three participants were white, one was South Asian, and one did not report. Ages ranged from 45 to 53, and all had at least some college education. The two participants who reported listed their household incomes as over \$100,000 per year. Transportation was a mixture of public and driving themselves when able. Most lived in single family homes with others. One needed help with ADLs all the time, another some of the time, and another did not need help (one did not answer). The MS Society staff member thought the people in our group represented their membership well.

Discussion Points

- Found information through:
 - Friends, peer support groups
 - Doctor
 - At MS Society
 - At Board of Social Services
 - Abilities expo
 - By walking around neighborhood

- Expense of being disabled not taken into account when determining eligibility for public programs
 - Those with MS often middle class, but have high drug costs and experience the Medicare part D “donut hole”
- All felt services were inadequate
 - Example: Problems with transportation for medical appointments—very limited hours available, the drivers can’t wait for return, turns into huge ordeal
 - Example: If consumers don’t need personal assistant every day, never get to top of waiting list, but need is still there
- All thought the organization of information was problematic—fragmented, no centralized source
- Disagreement in group—savvy internet users felt that the primary problem was lack of services rather than finding information about services; those who relied on phone calls or other methods had more problems finding information
 - Barriers included getting a lot of misinformation, phone calls not returned
 - One participant found that the county Office on the Disabled did not have much information
 - One participant mentioned that the MS Society list of contractors to make home modifications was outdated; another participant noted that this was improving with new volunteers to work on it
 - Confusion on overlap of Medicare, Medicaid, Social Security Disability (SSD), Supplemental Security Income (SSI)
- Lumping younger people with disabilities in with seniors is problematic—hard to tell which services are for seniors only
 - Senior Gold program sounds like for seniors only but younger people with disabilities are eligible
 - PAAD—took a long time for one group member to find out that they were eligible for this (other group members had not heard of)
 - Both of these services are listed on Department of Health and Senior Services (DHSS) website, but not on DDS (Division of Disability Services)
- Headaches with applying for programs—repeatedly asked for information that was provided, wonders if state trying to save money by foot-dragging
 - PAAD program—didn’t realize renewal was necessary; can’t get through to 800 number (better luck with local number)
- Problem of resource availability, different levels of government blame each other instead of offering solutions

Suggestions for publicity

- Office in each county with information and resources—take advantage of local knowledge (disagreement—others thought compartmentalization was bad and wanted state uniformity)
- Resource directory with more information than phone numbers so people would know whether to call

- Custom mailings to people with disabilities based on information they have provided to government offices.

North Jersey – Short Hills

We held a group in the afternoon of June 23, 2008 at the Christopher and Dana Reeve Foundation in Short Hills. Participants included three women (one by phone) and five men. One participant was blind, and all others were wheelchair users. Three aides attended with the consumers for whom they worked. The consumers were mostly white, with one Asian and one Latino. Ages ranged from 21-57. Incomes ranged from very low to more than \$100,000 per year. Several participants were very internet savvy. One participant was an employee of a county Office on Disability.

Discussion Points

- Finding information
 - Participants reported getting useful information from staff at Kessler Rehabilitation, from support groups there, and from a bulletin board there (which has apparently been removed, to their dismay)
 - Participants reported better luck getting personal aides from word of mouth than by using agencies
 - For housing, participants had used the NJ Housing site (<http://www.njhousing.gov/>, visited November 26, 2008), but had not found anything there. The one participant who found an affordable, accessible apartment had followed its development over several years and continually called to follow up, with assistance from a family member. Another found housing through a Lion's club.
 - Participants reported using their County Office on Disability (several knew the participant who was employed there)
 - DDS has an online directory that people reported using http://www.state.nj.us/humanservices/dds/RD_08.pdf (visited July 9, 2008)
 - Some used internet message boards such as
 - New Mobility <http://www.newmobility.com/> (visited July 9, 2008)
 - Power quad <http://www.powerquad.net/forum/sitenews.asp> (visited July 9, 2008)
 - Care Cure Community <http://sci.rutgers.edu/> (visited July 9, 2008)
 - Participants reported finding the annual abilities expo useful <http://nyc.abilitiesexpo.com/iaenyc/v42/index.cvn> (visited July 9, 2008)
 - One participant reported calling the school that he had attended, the NJ Commission for the Blind, for various resources (he heard about the Commission from a friend)
 - One participant reported checking with Medicaid for participating practitioners
 - Participants mentioned the Paralysis Resource Guide put out by the Christopher and Dana Reeve Foundation--available online at

<http://www.nxtbook.com/nxtbooks/crf/paralysisresourceguide/> or see <http://www.paralysis.org/site/c.erJMJUOXFmH/b.1314533/> to order (visited July 14, 2008)

- Participants mentioned internet advocacy groups and local support groups (such as for post-polio) as well as Centers for Independent Living
- United Spinal was mentioned <http://www.unitedspinal.org/> (visited July 14, 2008) formerly known as Eastern Paralyzed Veterans Association (mandate broadened)
- Several participants were very internet savvy and reported using search engine Google to find much of what they needed
- NJ Transit has a section on accessible services that one participant reported using
- One participant used and liked 211
- Information problems
 - Wheelchair users reported problems finding information about practitioners (especially dentists) with accessible offices, and often relied on word of mouth for this. For these consumers, being able to choose from a set of accessible practitioners rather than having to call around and ask would save time.
 - One participant reported a lack of discharge planning and had felt on his own to find resources—family friends had helped purchase equipment he needed
- Service gaps
 - Lack of holistic advice—one participant bought a specialty van that he wound up not liking to drive, but he can't sell it because it is so customized. He really wishes someone had warned him of the consequences of the purchase, which he is still paying for.
 - Shortfalls of public transportation discussed—if not on bus line, can't get Access Link (if too close to bus stop also). Have to wait outside 20 minutes ahead, a problem in bad weather when people can be waiting 40 minutes. One participant on bus for an hour to get two blocks (circuitous routing based on who got in first rather than who was closest)
 - High out of pocket expenses (hundreds for dollars for bowel supplies, etc.)
 - Section 8 announcements should be in alternate print for blind people
- Service success
 - A participant reported satisfaction using transport paid by Medicaid (medical only)
- Discussion of insurance and working
 - Some felt Medicaid better than private, but depended what options private offered (HMOs more limited). Copays can make private insurance expensive
 - One participant took less than market pay for his work to keep Medicaid

Suggestions for publicity

- Solicit email addresses for information updates (don't share addresses—i.e., don't have them show with email).

- Design good websites for those with access and provide directories for those who don't have access
- Better followup from hospitals to make sure people with disabilities doing okay—people can fall through the cracks.
- For blind people, mail information to them

South Jersey – Mount Holly

We visited a support group for people with Reflex Sympathetic Dystrophy Syndrome (RSD), which is now known as Complex Regional Pain Syndrome (CRPS) in the evening of July 16, 2008 at Virtua Hospital in Mount Holly. The support group leader had contacted participants to let them know we would attend. Participants included three individuals with RSD (two women and one man, all long-term participants) and four family members of an individual diagnosed with RSD (two men and two women, one of whom had lupus). All were white and in their mid forties up to age 60. One participant reported a low income (less than \$20,000 per year), two reported a moderate income (\$40,000 to \$60,000 per year) and the remainder reported incomes over \$100,000 per year.

Discussion Points

- People found the group through doctors or physical therapists, or by searching the internet for information about the disease. The group leader also tended to find people just by striking up conversations with people in the community (noticing people with pain, etc.)
- People in the group tended to get information from the group and from doctors
- All in the group with RSD were unable to work and either had worker's compensation or had qualified for SSD
- Dealing with lesser known disease—pain, changing conditions, tend to have to give up jobs, get on SSD
 - going from doctor to doctor, more time here than a better known condition
 - dealing with uninformed/opportunistic cure purveyors
 - condition often involves strong pain meds—vulnerable to addicts seeking supply or dealers seeking source
 - because disease disabling but poorly understood, get people wanting information to try and get out of work
 - support group discusses treatments, not services—group regulars coming for years, others in and out
- All in group had family support; group leader stated that sometimes people called asking for resources and she had no idea where to send them (we sent her information)
 - Specifically, people had problems with transportation because insurance would not pay for this, and some people had financial problems while they were waiting for social security disability benefits
- The process of getting on SSD can be intimidating

Suggestions for publicity

- DDS information and referral has the group contact information—can give information to group leader

People with Developmental Disabilities

South Jersey -- Vineland

We held one focus group at the Developmental Center in Vineland. The group met in the afternoon on June 11, 2008. Participants were recruited by the transition coordinator at the center, and included three consumers (all women) who had transitioned from the center to live in community settings, and two consumers who wanted to transition from the center. This center is not yet adopting the new Olmstead process of transition planning. Other group participants included center staff who work with residents (three), group home and agency staff who work with community residents (four), family members (one), and a representative from the NJ Department of Developmental Disabilities (one). Of the consumers, three were black and two were white. Of the other participants, five were black and four were white.²⁵

Discussion Points

- Residents are consulted about what kinds of services they will want in the community, but the actual finding and securing of those services is done by center staff and community agencies rather than by residents or their families
- In this group discussion, the consumers wanting to transition indicated that participation in work, worship and social activities was important to them, and thus transportation to these activities was key. Medical and counseling services were also important so that consumers could maintain themselves in a community setting.
- Consumers who had transitioned and the agencies present described the kinds of activities in which they participated—in these cases, the agency provided transportation for the consumers (to work and for social outings)
- Agencies that are serving similar clients build relationships in communities over time and this is generally how they locate service providers. They described barriers in terms of the time involved in getting consumers who wanted to transition approved for a waiver slot and finding community providers who accepted Medicaid. They found DDD prioritization policies mysterious.
- The NJ DDD staff member informed the group of a state web site listing providers who accept Medicaid.²⁶ Not all the agency staff had internet access at work, however.

Central Jersey – Lawrenceville

We held a group in the morning of July 30, 2008 in the public library in Lawrenceville. The Family Support Network publicized the meeting, which was attended by eight parents (three dads and five moms—none with children in common) and six service providers (all women). From the group discussions, it appeared that some participants had traveled to the

group from a different region (at least one from North Jersey and one from South Jersey). However, because our surveys were not designed to measure where people were from, we classified all in this group as Central Jersey in our tables. All group participants were white. Ages ranged from the early twenties to the mid seventies, with the majority of participants in their forties or fifties. Incomes ranged from below \$20,000 per year to over \$100,000 per year. Almost all were college graduates with several holding advanced degrees. Many are advocates who have been involved with the system for some time. An observer from the Department of Developmental Disabilities also attended the group.

Discussion Points

- People found that personal networking, including internet support groups, was helpful
- Misinformation common from DDD caseworkers
 - High turnover, high caseloads, some lying
 - Impression that DDD hiding from people in need because they don't have the services.
 - Providers said they had problems at times getting accurate information from DDD
- Parent experiences searching for information
 - Don't know what questions to ask
 - Resource directories are overwhelming unless you know exactly what you are looking for
- Full-time job for parents to find and manage services
 - every parent has to do all the research themselves—reinventing wheel
 - frustration at not finding needed services in time
 - Parents scared for vulnerable disabled children who cannot communicate well
- Information doesn't get to many who need it
 - Those who are disadvantaged in particular, but even well connected people miss things
 - Fragmented/scattered system
 - Silos that don't connect
- Limited services—gatekeepers whose job is to say no, won't give names or be accountable for information given
- Suggestions for parent involvement
 - Delicate balance between empowering families and pushing work on them
 - Parents need to advocate to fund services
 - Need system for family members to share information (some thought this was shoving work onto families)
- Self direction—reaction to Real Life Choices
 - Families dislike some aspects—would like more guidance in seeking services, a buffer between worker and them (afraid for child's health to complain—nonverbal children can't say what's going on)
 - Participants liked original support brokers more than what is in place now (just give phone #'s)

- Hard to gather information at community level—i.e., may be a nursery school that is friendly toward disabled children but does not advertise itself as such—who will know about this?
 - Had suggested community resource person with access to all resources, DDD turned down.
 - Not just gather information but facilitate connections

Suggestions for publicity

- Agencies should do more outreach—know who we are
- Potential with family support council, can touch many families, hoping they can get back on their feet
- DDD, DVR, schools should coordinate better
- Outreach to doctors—one group member participated in developing a brochure that was distributed statewide to pediatricians, hospitals, health centers and community organizations (200,000 copies)²⁷
- Personnel assigned to an area that would help parents navigate the system, similar to Family Consultant Program in Pennsylvania²⁸

North Jersey – Union City

We held a group in the morning of November 14, 2008 at the ARC of Hudson County in Union City. The Executive Director (ED) of the ARC recruited clients and hosted the group. She also participated and translated for the participants. We had five participants, all Latino women and mothers of children with disabilities. One of the daughters attended the meeting, but did not (does not) speak. Ages of participants ranged from 43 to 72 (4 in their 40s or 50s). Three spoke only Spanish at home while two spoke both Spanish and English. All primarily used public transportation and lived in some kind of multifamily housing, common for this part of New Jersey. All provided care for daughters, all of whom lived at home and had for the duration of their lives—the daughters ranged in age from 6 to 35, with most in their 20s or 30s.

Discussion Points

- Problems finding providers who took Medicaid (emailed ED link to Medicaid providers information)
- Insensitivity of medical providers to their daughters' disabilities (i.e., making a person with autism wait for an hour); refuse to support disabled parking permit application for daughter—hazardous to get her through a parking lot (knows others who have permits).
- Thought people with disabilities should have more preferences in access to housing (emailed ED resources on housing, including how to advocate for preferences for disabled people)
- DD caseworkers not a source of much information
- Got information from schools, ARC, news in Spanish <http://www.nj.com/elnuevo/> , SPAN <http://www.spannj.org/> , COSAC <http://www.njcosac.org>
- Don't get enough homemaker hours—stress to caregiver who is single mom

- Financial burden—one mom has to pay \$5.60 per day for transportation for her daughter to adult day (Medicaid pays for the adult day services)
- Language barrier
 - Difficult to advocate for child—one mother had problems with a school not providing good services and a noncooperative bus service that put her nonverbal daughter toward the back where she was vulnerable to abuse; took her out of school.
 - Another woman was being pursued for collection on a guardianship issue—brought the letter (in English)—others thought DDD should pay and suggested she call her caseworker
 - People hang up on them when they call places
 - Educational plans received in English; parents can't understand
- Had not used 211
 - ED had gotten calls, some inappropriate referrals
 - Would be nice to have information on accessible places (physically or just welcoming of those with disabilities)

Suggestions for publicity

- Recommendations
 - Directory in book form for services (emailed information on DDS resource book)
 - Since kids are registered with the state, send information (in language parents speak)—target information to eligible people
 - Come to ARC to speak (ARC of NJ researches and disseminates now)
 - Provide funds for agencies to inform their populations
 - Bilingual staff

Research Methodology

Focus Groups

Focus groups or group interviews bring together a group of people to discuss a topic of common interest. Facilitators should make clear that the purpose of the group is to share perspectives, rather than coming to a consensus. The process of group discussion often yields richer data than individual interviews as participants add to others' views and think more deeply about their own perspectives. This format also allows participants to shape the discussion more than is possible with a survey or interview that is closely controlled by the interviewer—this can allow researchers to learn new information and reshape their understanding of a topic.²⁹

Recruiting

The state agencies involved with the grant provided the researchers with contacts of community groups who agency staff felt would be able to recruit participants.³⁰ Researchers

contacted the community groups and provided information on the project and an idea of the questions to be asked. The community groups recruited participants or allowed researchers access to pre-existing meetings to conduct the groups.

Facilitation

Discussions were held in the community or conference rooms of the community groups or in other places where the groups generally met (public library, hospital, etc.). Two researchers attended each group discussion, and an audio recording was made of the discussion in addition to the researchers' notes.³¹ Researchers provided participants with an informational handout about the group containing contact information for the researchers and the Rutgers Institutional Review Board.³² Researchers handed out an optional anonymous survey to record participants' demographic information (results in Tables 1 through 5 following this section).

Analysis

Tables

The researchers used a spreadsheet to tabulate the anonymous survey results. In some cases researchers used their notes and/or recollections to add to the data provided by survey responses (regarding gender, for example, which was not asked on the survey, or to make age or racial/ethnic classifications where we were certain).

Themes

During each group, one researcher concentrated on taking detailed notes on a laptop computer while the other researcher focused on facilitating the discussion and taking handwritten notes on important points. Soon after each group, the researchers verified that the audio recording had been successful and reviewed the notes, filling in any gaps by listening to the audio recordings. From these notes, the researchers distilled the discussion points for each group (presented in the previous section of this document). Working from the discussion points as well as our recollections of discussion intensity, we looked for commonalities across groups. The themes we present were self-evident both overall and in the subgroups.

Table 1: Participant Characteristics, All Groups

		Number	Percent
Region of Group			
	North	36	37%
	Central	30	31%
	South	31	32%
Type of Group			
	Seniors	33	34%
	People w/ Physical Disabilities	19	20%
	People w/ Developmental Disabilities, Caregivers or Service Providers	32	33%
	Caregiver Coalition	13	13%
Race/Ethnicity			
	White	58	60%
	Black	15	15%
	Latino	11	11%
	Other	5	5%
	No Answer	8	8%
Income			
	Less than \$20,000 per year	23	24%
	\$20,000 to \$39,999 per year	12	12%
	\$40,000 to \$59,999 per year	14	14%
	\$60,000 to \$79,999 per year	2	2%
	\$80,000 to \$99,999 per year	6	6%
	\$100,000 or more per year	16	16%
	No Answer	24	25%
Age			
	Less than 30	6	6%
	30-44	15	15%
	45-59	30	31%
	60-75	29	30%
	More than 75	10	10%
	No Answer	7	7%
Education			
	Less than high school	8	8%
	High school graduate	13	13%
	2 year degree or some college	8	8%
	4 year college degree	23	24%
	Advanced degree	17	18%
	No Answer	28	29%
Gender			
	Women	74	76%
	Men	23	24%

Table 2: Participant Characteristics, Caregiver Groups

		Number	Percent
Region of Group			
	North	18	69%
	Central	8	31%
Type of Participant			
	Caregiver Coalition Member (Morris Cty)	13	50%
	Caregivers for Children with DD	13	50%
Race/Ethnicity			
	White	20	77%
	Black	1	4%
	Latino	5	19%
Income			
	Less than \$20,000 per year	3	12%
	\$20,000 to \$39,999 per year	2	8%
	\$40,000 to \$59,999 per year	8	31%
	\$60,000 to \$79,999 per year	0	0%
	\$80,000 to \$99,999 per year	2	8%
	\$100,000 or more per year	3	12%
	Could not determine	8	31%
Age			
	41-65	23	88%
	66-75	1	4%
	More than 75	2	8%
Education			
	Less than high school	2	8%
	High school graduate	2	8%
	2 year degree or some college	5	19%
	4 year college degree	5	19%
	Advanced degree	4	15%
	Could not determine	8	31%
Gender			
	Women	21	81%
	Men	5	19%

Table 3: Participant Characteristics, Older Adult Groups

		Number	Percent
Region of Group			
	North	10	30%
	Central	12	36%
	South	11	33%
Race/Ethnicity			
	White	15	45%
	Black	6	18%
	Latino	5	15%
	Other	3	9%
	No Answer	4	12%
Income			
	Less than \$20,000 per year	13	39%
	\$20,000 to \$39,999 per year	7	21%
	\$40,000 to \$59,999 per year	1	3%
	\$60,000 to \$79,999 per year	1	3%
	\$80,000 to \$99,999 per year	1	3%
	\$100,000 or more per year	2	6%
	No Answer	8	24%
Age			
	60-75	21	64%
	More than 75	8	24%
	No Answer	4	12%
Education			
	Less than high school	5	15%
	High school graduate	8	24%
	2 year degree or some college	1	3%
	4 year college degree	6	18%
	Advanced degree	4	12%
	No Answer	9	27%
Gender			
	Women	27	82%
	Men	6	18%

Table 4: Participant Characteristics, Groups of People with Physical Disabilities

		Number	Percent
Region of Group			
	North	8	42%
	Central	4	21%
	South	7	37%
Race/Ethnicity			
	White	14	74%
	Latino	1	5%
	Asian	1	5%
	No Answer	3	16%
Income			
	Less than \$20,000 per year	2	11%
	\$20,000 to \$39,999 per year	1	5%
	\$40,000 to \$59,999 per year	3	16%
	\$60,000 to \$99,999 per year	0	0%
	\$100,000 or more per year	7	37%
	No Answer	6	32%
Age			
	Less than 30	2	11%
	30-44	3	16%
	45-59	11	58%
	60-75	1	5%
	No Answer	2	11%
Education			
	Less than high school	1	5%
	High school graduate	2	11%
	2 year degree or some college	2	11%
	4 year college degree	4	21%
	Advanced degree	3	16%
	No Answer	7	37%
Gender			
	Women	9	47%
	Men	10	53%

Table 5: Participant Characteristics, Groups of People with Developmental Disabilities, Their Caregivers and Service Providers

		Number	Percent
Region of Group			
	North	5	16%
	Central	14	44%
	South	13	41%
Type of Participant			
	Person with a Developmental Disability	5	16%
	Family Member of a Person with DD	14	44%
	Service Provider for People with DD	13	41%
Race/Ethnicity			
	White	17	53%
	Black	8	25%
	Latino	5	16%
	No Answer	2	6%
Income			
	Less than \$20,000 per year	7	22%
	\$20,000 to \$39,999 per year	3	9%
	\$40,000 to \$59,999 per year	5	16%
	\$60,000 to \$79,999 per year	1	3%
	\$80,000 to \$99,999 per year	3	9%
	\$100,000 or more per year	4	13%
	No Answer	9	28%
Age			
	Less than 30	4	13%
	30-44	12	38%
	45-59	11	34%
	60-75	3	9%
	More than 75	1	3%
	No Answer	1	3%
Education			
	Less than high school	2	6%
	High school graduate	3	9%
	2 year degree or some college	0	0%
	4 year college degree	9	28%
	Advanced degree	6	19%
	No Answer	12	38%
Gender			
	Women	27	84%
	Men	5	16%

Endnotes

¹ Eleven members of the Caregiver Advisory Panel responded by email or on paper to our questions because they were unable to attend the meeting—see page 13 for details.

² This terminology was used by a couple of participants in one of our groups of people with physical disabilities. We later noticed that a guide put out by the Morris County Caregivers Coalition used this same term to describe its goals. For the guide, see <http://www.uwmorris.org/priorities/caregiveresource.html> (visited December 17, 2008).

³ We did not hear any comments about this site, but we did not specifically probe for it.

⁴ An example of web standards for accessibility is the Web Content Accessibility Guidelines of the World Wide Web Consortium, last updated December 11, 2008 (see <http://www.w3.org/TR/WCAG20/>). For tips on translating for non-English speakers, see <http://www.hcbs.org/files/52/2562/Translation.pdf> (visited December 17, 2008).

⁵ See <http://www.get2human.com/gethumanStandard.htm> (visited December 1, 2008).

⁶ This stands for New Jersey Easy Access Single Entry (see <http://www.state.nj.us/health/senior/sanjease.shtml>, visited March 25, 2009).

⁷ See http://www.state.nj.us/humanservices/dds/RD_08.pdf (visited December 1, 2008).

⁸ See <http://www.co.camden.nj.us/government/offices/seniors/disabledguide.pdf> (visited December 17, 2008).

⁹ See <http://www.uwmorris.org/priorities/caregiveresource.html> (visited December 17, 2008).

¹⁰ For example, in several cases people seemed angry at state agencies for not funding services appropriately without understanding the secondary role agencies play in funding decisions—only a few participants mentioned the need to advocate for funding with elected officials.

¹¹ See Walling, D.R. (2007, December). “The Return of Civic Education.” *Phi Delta Kappan* 89(4): 285-289. Accessed December 1, 2008 from:

<http://www.civiced.org/pdfs/centerInNews/Walling-CivicEdArticle.pdf>

¹² See http://www.state.nj.us/humanservices/dds/RD_08.pdf (visited December 1, 2008).

¹³ See Fortin, C. (2008, March 24). “Helping families find the resources they need.” ARC of NJ blog hosted on nj.com (visited December 1, 2008).

http://www.nj.com/helpinghands/arc/index.ssf/2008/03/helping_families_find_the_reso.html ; Brochure downloaded December 1, 2008 from: http://blog.nj.com/helpinghandsimpact_arc/2008/03/final%20healthhelp%20March%202008.pdf .

¹⁴ See <http://www.google.com/support/webmasters/bin/answer.py?hl=en&answer=35291> (visited December 1, 2008).

¹⁵ See list of regions under section on Affirmative Marketing at:

<http://www.state.nj.us/dca/affiliates/coah/resources/adminresources.html> (visited November 24, 2008).

¹⁶ See <http://www.get2human.com/gethumanStandard.htm> (visited December 1, 2008). For the story behind the site, see McGregor, J. (2008, February 21). “Rebel with a stalled cause.” *Business Week Magazine*, available at

http://www.businessweek.com/magazine/content/08_09/b4073052446903.htm?chan=magazine+channel_in+depth (visited December 2, 2008).

¹⁷ See accessibility standards: Web Content Accessibility Guidelines of the World Wide Web Consortium, last updated December 11, 2008 (see <http://www.w3.org/TR/WCAG20/>).

¹⁸ See State of NJ, Housing Choice Voucher Administrative Plan (2007) <http://www.state.nj.us/dca/dh/pubs/administrativeplanfy2008.pdf>, pdf page 20, document page 2-1. Connecticut allows interested parties to register for Section 8 waiting list openings—see http://www.das.state.ct.us/Business_svcs/HCPV/WL_Register_Form.asp (visited December 2, 2008).

¹⁹ See Americans with Disabilities Act (ADA) Paratransit Eligibility Manual (1993, September). DOT-T-93-17. Accessed December 2, 2008 from <http://ntl.bts.gov/DOCS/ada.html>. For information on NJ Access Link, see http://www.njtransit.com/as_al.shtml (visited December 2, 2008).

²⁰ The Lawrenceville group was composed of both family caregivers and service providers. We have only included the family caregivers in this group. Because our anonymous surveys did not distinguish family caregivers from service providers, we had to collapse the age category and note as undetermined responses regarding income and education for this table.

²¹ See information about the Caregivers Coalition and the Advisory Panel at <http://www.uwmorris.org/priorities/caregiverscoalition.html> (visited July 7, 2008).

²² Participants did not have a copy, but we think this may be the guide they mentioned: <http://www.co.camden.nj.us/government/offices/seniors/disabledguide.pdf> (visited December 17, 2008).

²³ Found information at <http://www.camdencounty.com/government/offices/seniors/outreach.html> (visited August 26, 2008): “Golden Voice Newspaper, 856-854-1400, 732 Haddon Avenue, Collingswood, NJ 08108. Mailing Address: P.O. Box 103; Audubon, NJ 08106. A non-profit publication dedicated to the interest of Camden County's Senior Citizens. Mailed to subscribers for \$3.00 per year.”

²⁴ See <http://www.co.bergen.nj.us/ParksPDF/CountyDirectory.pdf> for the 2008 version (visited December 17, 2008)

²⁵ Our summary statistics in Table 1 do not include the participant from DDD.

²⁶ See New Jersey Medicaid Provider Directory, <http://www.njmms.com/providerDirectory.aspx> (visited July 9, 2008)

²⁷ See Fortin, C. (2008, March 24). “Helping families find the resources they need.” ARC of NJ blog hosted on nj.com (visited December 1, 2008). http://www.nj.com/helpinghands/arc/index.ssf/2008/03/helping_families_find_the_reso.html; Brochure downloaded December 1, 2008 from: http://blog.nj.com/helpinghandsimpact_arc/2008/03/final%20healthhelp%20March%202008.pdf.

²⁸ See <http://www.oit.state.pa.us/accessiblepa/cwp/view.asp?A=2&Q=48961> (visited December 18, 2008).

²⁹ For more information on focus groups, see Krueger, R. (1994) *Focus Groups: A Practical Guide for Applied Research*, 2nd ed. Sage Publications, Thousand Oaks, CA; Merton, R. K., Fiske, M.,

and Kendall, P. L. (1990) *The Focused Interview: A Manual of Problems and Procedures*, 2nd ed. The Free Press (Macmillan), New York; Morgan, D. (1988) *Focus Groups as Qualitative Research*, (Sage University Paper Series on Qualitative Research Methods, Vol 16). Sage, Newbury Park, CA.

³⁰ In one case the researchers contacted a group not suggested by a state agency (ARC of Hudson County).

³¹ The Mt. Holly group was not recorded because the support group conversation began before we could ask permission, and we didn't want to interrupt the flow of the group to do so.

³² See copy in Appendix, page 37.

Appendix: Handout, Surveys, Moderation Guide

Information Sheet.....Page 37

This sheet was given to participants at each session.

Surveys.....Page 38

These surveys were distributed at the start of each session. Participants were instructed that the surveys were voluntary, with the purpose of knowing the participant demographics, and were instructed not to put their names on them. The caregivers version was used in the Morris County Caregivers group and the Union City group. It was not used in the Lawrenceville group because we had only brought the regular version.

CaregiversPage 38

OtherPage 39

Moderation guide.....Page 40

This guide was submitted to the Access /Awareness Workgroup to ensure that these were the kinds of questions for which answers were desired. We used this as a guide for discussions. It was not usually distributed to participants, though we often sent it to organizers to let them know what we would want to discuss. One group organizer emailed this to participants who were not available to attend, and some elected to provide written responses.

Focus Group Information

Purpose of group

New Jersey has received a federal grant to improve its system of long-term care services to residents with chronic health conditions. As part of this, the state is examining how residents get information on services to help make decisions about how to put the word out. The state has hired Rutgers Center for State Health Policy to conduct the focus group and analyze the results.

Your role

You are here today to give your feedback about these issues. Your participation is completely voluntary and involves attending this meeting for approximately 1 hour and 30 minutes and expressing your views on how you find information about the long-term care services you need and how you would prefer to get information. This information will help the state know how to properly publicize the services it funds. There are no right and wrong answers here. Each of you is the expert on your situation, and we want to hear everyone's experiences and opinions.

Maintaining your privacy

Strict confidentiality will be maintained. The group interview will be audiotaped but no individuals will be identified on the tape or the transcripts. Please do not identify yourself or anyone else on the tape during the discussion. If anyone is accidentally identified, we will stop and rewind the tape to ensure confidentiality. Once transcribed the tape will be destroyed. No individuals will be named in any reports of results.

Contact information

After our meeting, if you have questions about this study please contact Jennifer Farnham at Rutgers University—Email: jfarnham@ifh.rutgers.edu; Phone: 732-932-4675. If you have questions about your rights as a research participant, contact the Rutgers University sponsored programs administrator, Phone: 732-932-0150 ext. 2104; email: humansubjects@orsp.rutgers.edu.

Background Information

We are asking you to provide the following background information so that we can describe participants as a group. You do not need to put your name on this document. No individuals will be identified in any reports. Your confidentiality will be protected.

1. What is your age? _____ years
2. What is the last grade or degree you completed in school? _____
3. How would you describe your race/ethnic background? _____
4. What is your approximate household income? (Choose one):
 - ___ Less than \$20,000
 - ___ \$20,000 - \$39,999
 - ___ \$40,000 - \$59,999
 - ___ \$60,000 - \$79,999
 - ___ \$80,000 - \$99,999
 - ___ \$100,000 or more
5. What type of transportation do you use the majority of the time? (Choose one)
 - ___ Car that I drive
 - ___ Car driven by someone else
 - ___ Cab
 - ___ Bus/Train
 - ___ Other (describe _____)
6. How would you describe your dwelling? (Choose one)
 - ___ Apartment/condo
 - ___ Single family home
 - ___ Assisted living
 - ___ Nursing home
 - ___ Other (describe _____)
7. How many people live in your home? _____
8. Do you live with? (choose all that apply)
 - ___ Spouse
 - ___ Your children
 - ___ Other (describe _____)
9. Do you require assistance with any activities of daily living, such as getting out of bed, dressing, eating, or using the bathroom?
 - ___ Yes
 - ___ No

Thanks very much. Please return this at the end of the session.

Background Information--Caregivers

We are asking you to provide the following information so that we can describe participants as a group. You do not need to put your name on this document. No individuals will be identified in any reports.

1. What is your age? _____ years
2. What is the last grade or degree you completed in school? _____
3. How would you describe your race/ethnic background? _____
4. What is your approximate household income? (Choose one):
 Less than \$20,000 \$60,000 - \$79,999
 \$20,000 - \$39,999 \$80,000 - \$99,999
 \$40,000 - \$59,999 \$100,000 or more
5. What type of transportation do you use the majority of the time? (Choose one)
 Car that I drive Cab
 Car driven by someone else Bus/Train
 Other (_____)
6. How would you describe your dwelling? (Choose one)
 Apartment/condo/other multifamily Single family home
 Other (_____)
7. How many people live in your home? _____
8. Do you live with? (choose all that apply)
 Spouse
 Your children
 Other (describe _____)
9. What is your relationship to the person(s) you are caring for?

10. How long have you been caring for this person(s)? _____ years
11. Where does the person you are caring for live (with you, group home, etc.)?

12. What is the age and gender of the person you're caring for? _____ years male female
13. What is the major health condition of the person(s) you're caring for?

Thanks very much. Please return this at the end of the session.

New Jersey Focus Group Questions

Draft submitted October 23, 2007 to NJ STG Access/Awareness Co-Chairs by Jennifer Farnham and Amy Tiedemann of Rutgers Center for State Health Policy

Introduction [goal: explain purpose of focus group]

New Jersey has received a federal grant to improve its system of long-term care services to residents with chronic health conditions. As part of this, the state is examining how residents get information on services to help make decisions about how to put the word out. You are here [today/tonight] to give your feedback about these issues. Your participation is completely voluntary and involves attending this meeting for approximately 1 hour and 30 minutes and expressing your views on how you find information about the long-term care services you need and how you would prefer to get information. This information will help the state know how to properly publicize the services it funds. There are no right and wrong answers here. Each of you is the expert on your situation, and we want to hear everyone's experiences and opinions.

Strict confidentiality will be maintained. The group interview will be audiotaped but no individuals will be identified on the tape or the transcripts. Please do not identify yourself or anyone else on the tape during the discussion. If anyone is accidentally identified, we will stop and rewind the tape to ensure confidentiality. Once transcribed the tape will be destroyed. No individuals will be named in any reports of results. After our meeting, if you have questions about this study please contact Jennifer Farnham at Rutgers University, Phone: 732-932-4675. If you have questions about your rights as a research participant, contact the Rutgers University sponsored programs administrator, Phone: 732-932-0150 ext. 2104; email: humansubjects@orsp.rutgers.edu.

Focus Group Question Guide

- **What are the different types of services that you look for information on?** [we may find different strategies for different services—asking health professionals about health related services, others for more “social” services, etc.]
- **What is the main way that you find out about service [X]? (Refer to categories of service mentioned above: – e.g., medical services, transportation)**
 - Follow ups:
 - are there other ways you find out about this service that haven't been mentioned here?
 - If health care provider, how is information given (verbal, brochures)?
 - If TV/radio, what channel and what times?
 - If newspaper, which one and what section?
 - If newsletter, what group?
 - If bulletin board, where located (organization, location within organization)?
 - If community presentation—where located (public library, CIL, etc.)?
- **Have you, or has someone on your behalf, made phone calls to look for information on services?**
 - Follow ups:

- Did you yourself call, or did someone call on your behalf?
 - If so, who? [relative, friend, social worker, etc.]
 - Where have you called?
 - How did you get the number to call?
 - What kinds of services were you looking for?
 - Experience with calling--have you gotten an answer, or just referred somewhere else to get information?
 - **Barriers experienced with calling?**
 - No TTY
 - Language
 - other
 - [if not mentioned] Have you called 211 for information?
 - [for those who have called 211] – Experience with calling--have you gotten an answer, or just referred somewhere else to get information?
 - [for all] how many phone calls would you say you had to make to get the information you needed?
- [Once 211 mentioned, if seems unfamiliar to some] **Have you heard of 211?**
 - Follow ups:
 - How did you hear?
 - Who did you hear it from?
 - What did you hear about it?
- **Have you, or has someone on your behalf, searched the internet to look for information on services?**
 - Follow ups:
 - Did you yourself look, or did someone look on your behalf?
 - If so, who? [relative, friend, social worker, etc.]
 - Where have you looked?
 - How did you find or get to the sites you looked at?
 - What kinds of services were you looking for?
 - Experience with looking—how quickly were you able to actually get to the service provider?
 - **Barriers with looking**
 - Computer speed/access to computer
 - Visual presentation of web site
 - Not good for visually impaired
 - Language problems
 - Other
 - [if not mentioned] Have you looked at the nj211 site for information?
 - [for those who have looked at nj211] – Experience—how many subsequent clicks or calls did it take to get to the service provider?
- **What would be your main recommendation to the state about improving the information available to consumers?**
 - Follow ups [order depends on previous discussion—is finding info an issue, or is the quality of info the main issue]:
 - Improve the quality of information that providers have [i.e., people call 211 but don't get what they need]

- Better advertising of where to go for information
 - Strategies—return to main places where people get information and ask if that is where the information should go, or if people would prefer to go elsewhere
 - Where would information be most accessible to participants and useful to them

Note: If health care providers, like doctors, are a major source of information for participants we will ask specifically about experience with and barriers to receiving information from providers.