

Connecticut Council On Developmental Disabilities

2006 Stakeholder Study

FINAL REPORT

Prepared By:



May 1, 2006

Table of Contents

	<u>Page</u>
I. Study Background and Methodology	3
II. Connecticut Council on Developmental Disabilities	
A. Familiarity	7
B. Current Overall Image	8
C. Positive Perceptions	11
D. Negative Perceptions	15
III. State of Development Disabilities in Connecticut	
A. Recent Accomplishments	23
B. Priorities for the Near Future	25
IV. Conclusions and Recommendations	31

Part I
Study Background and Methodology

I. Study Background and Methodology

Study Background

In early 2006, the Connecticut Council on Developmental Disabilities (CT CDD) commissioned the Center for Survey Research and Analysis (CSRA) at the University of Connecticut to conduct an opinion study among its stakeholder population. CT CDD stakeholders include advocacy organizations, provider organizations, centers for independent living, state agencies, legislators and policy makers in the state of Connecticut.

The purpose of the study was to gauge among stakeholders:

- Awareness and familiarity with the Council and its work
- Perceptions of the Council
 - Overall image
 - What do they feel the Council is doing well?
 - What areas could the Council improve upon?
- General thoughts about conditions in Connecticut for people with developmental disabilities
 - What do stakeholders see as recent, noteworthy accomplishments in Connecticut for people with developmental disabilities?
 - What do they see as the priorities for the near future?

Methodology

The Council on Developmental Disabilities supplied CSRA with a list of 109 stakeholders to use as a base for the research.

Opinions were collected via two methods:

- *Method #1:* Three focus groups were held in West Hartford – two on April 4th and one on April 6th.
 - Stakeholders were recruited for the groups via a telephone solicitation (and follow-up letter)
 - Stakeholders were not informed that the study was being conducted for the CT CDD until the end of the session
 - The focus groups each lasted about 90 minutes
 - The groups were moderated by a trained UCONN focus group facilitator
- *Method #2:* In-depth telephone interviews were conducted during late March and early to mid April.
 - Interviews were conducted by senior CSRA interviewers
 - Interviews lasted, on average, between 15 and 25 minutes.

We wanted to include the thoughts and opinions of as many stakeholders as possible. Because many were too busy to attend a focus group, we utilized in-depth telephone interviews as well.

A total of 72 stakeholders participated in the study:

- 17 stakeholders participated in the focus groups
- 55 stakeholders completed in-depth telephone interviews

Since we gathered opinions from about 70% of the original list, the findings in this report can be seen as representative of the larger stakeholder group. All opinions discussed in the report are based on a critical mass of respondents (more than 20%) voicing that opinion. If an opinion was voiced by only one or a few respondents, that opinion is not included in this report.

All participants in the study were ensured confidentiality in order to illicit truthful opinions. Hence, no names are mentioned in the report, nor tied to any of the included quotes.

Part II

Connecticut Council on Developmental Disabilities

IIA. Connecticut Council on Developmental Disabilities -- Familiarity

The Connecticut Council on Developmental Disabilities is well known among its stakeholders. Almost all stakeholders (over 80%) who participated in the study said they were at least somewhat familiar with the Council. This familiarity stems from:

- Projects the Council has funded
- Knowing members of the Council
- Via e-mail “list serve”
- Word of mouth – many mention that Connecticut is a small state and the field of developmental disabilities is also small, so *“everyone in the field more or less knows who’s active in the field”* (quote from in-depth interview)

However, most stakeholders also feel the Council should do a lot more to communicate its activities and the projects that it funds – both to themselves (activists and professionals in the field) and to the general public. Many stakeholders feel the Council is *“too quiet”* and *“behind the scenes”* (quotes from in-depth interviews). Many also say that they, personally, would like to know more about:

- The Council’s core activities – when does it meet, what does it do?
- The Council’s decision-making process – how does it decide what to focus on from year to year?
- The projects the CT CDD is funding from year to year
- The Council’s plans for the future

Hence, while stakeholders are generally aware of the Council, most feel they do not know as much as they would like about its projects and activities.

Quote from focus group:

“They are very quiet. You have to work hard to know what they are doing. They don’t really advertise themselves.”

Quote from in-depth interview:

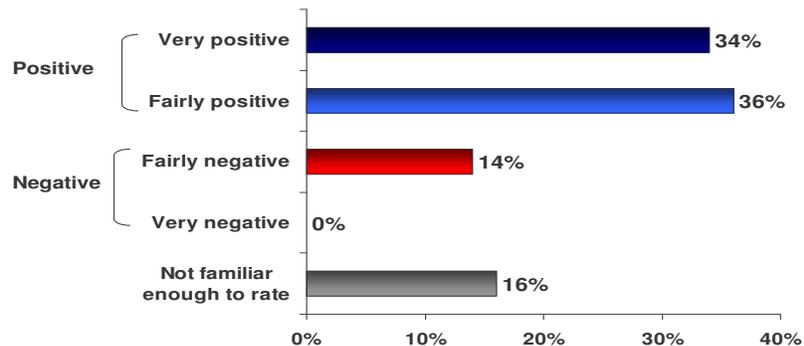
“I’m familiar with the DD Council, but not 100%. Like, I’m not sure how they decide what to fund from year to year. Seems their priorities change a lot. I would like to know how they decide on their priorities from year to year. That’s something I’d like to know -- how it works.”

There are more comments on the communications issue later in the report.

IIB. Connecticut Council on Developmental Disabilities – Current Overall Image

Overall, stakeholders have a positive image of the Council. They generally feel the Council is an important and constructive force active on behalf of people with developmental disabilities in Connecticut. In a rating exercise done in the focus groups and in-depth interviews, the vast majority of participants (70%) gave the Council positive ratings.

Question: “What is your overall impression of the Connecticut Council on Developmental Disabilities – would you say your overall impression is very positive, fairly positive, fairly negative or very negative?”



Base: among all stakeholders who participated in the study

Key reasons for the CT CDD’s positive ratings among stakeholders:

- Council membership and staff
 - Respect for individual Council members.
 - Applaud the inclusion of people with developmental disabilities on the Council.
 - Appreciate the diverse backgrounds of Council members.
 - Admire the skill, professionalism and friendliness of CT CDD staff.

- Funding
 - Believe the Council funds worthy projects, which significantly improve the lives of people with developmental disabilities.
 - Appreciate that the Council funds pilot projects – providing seed money to get programs and ideas off the ground.

- Advocacy
 - View the CT CDD as an effective advocate for people with developmental disabilities.
 - Admire the sharp focus that the CT CDD maintains on the issue of developmental disabilities.

Each of these areas are further developed later in the report, in the section entitled *Positive Perceptions*.

However, there is room for improvement in the Council's ratings. While stakeholders offer generally positive ratings, their enthusiasm is not as strong as it could be. For instance:

- Only 34% give the Council "very positive ratings"; while 36% give the Council "fairly positive ratings". For this 36%, there are several important perceived deficiencies within the CT CDD keeping them from giving the Council a top score.
- 14% give the CT CDD a "fairly negative rating". While this is a small percentage, it is still troublesome that one in seven stakeholders has a negative impression of the CT CDD.
- 16% are not familiar enough with the Council to offer a rating – showing the need for greater communications outreach to increase familiarity among stakeholders.

These ratings were taken early in the focus groups and interviews. The follow-up discussions in the focus groups and in-depth interviews shed light on why the ratings are moderately positive, but not quite as strong as the CT CDD would prefer. Some of the key complaints voiced by stakeholders:

- Weak on advocacy
 - Many feel the Council is timid and not as strong of an advocate as it could or should be.
 - The Council is seen by many as not being at the forefront of change.
- Structural problems – the CT CDD is seen as:
 - Too rigid in its organization.
 - Too strict in its grant making.
 - Not transparent enough.

- Communication challenges
 - The CT CDD often conveys a feeling of superiority when it interacts with others.
 - The CT CDD does not communicate enough to the stakeholder community

- Dissatisfaction with grant making activities
 - The CT CDD is seen as too short-term in its funding.
 - The CT CDD is seen as spreading its funding too thin.

All of these areas are explored in greater depth later in the report, in the section entitled *Negative Perceptions*.

II.C. Connecticut Council on Developmental Disabilities – Positive Perceptions

By and large, Stakeholders have a positive view of the Council. These positive opinions are grounded in three general areas: 1) Council membership and staff, 2) funding and 3) advocacy. While few stakeholders express support for *all* of these areas, most stakeholders express positive views about the Council in at least one of them.

Importantly, there were disagreements voiced regarding many of these positives characteristics. Those disagreements, or caveats, are covered in the next section of this report.

Area #1: Council Membership and Staff

Perceived positive: Diverse membership on the Council

Many stakeholders applaud the Council for having representation of diverse constituencies – state agencies, family members, community groups. They also appreciate that people with developmental disabilities and their immediate family members are on the Council – allowing for direct representation of these populations.

Quote from in-depth interview:

“There is a good, diverse group of people on the Council – with different backgrounds and experiences.”

Quote from focus group:

“I like that disabled people themselves are part of the decision making.”

Quote from in-depth interview:

“It is a well-rounded and enthusiastic group.”

Many stakeholders also appreciate the diversity of grants awarded to very different organizations and for varying purposes. Many feel the diversity of the Council helps ensure the diversity of projects funded.

Quote from in-depth interview:

“The Council gets involved in and funds a lot of different things – different programs and projects. I think that’s a direct reflection of the diverse people and backgrounds represented on the Council.”

Perceived positive: Capable and friendly staff

Many stakeholders voiced support for the current staff members at the CT CDD, often describing them as “competent”, “friendly”, “professional” and “good listeners.” Ed Preneta, CT CDD Director, was frequently singled out as a very good individual to work with.

*Quote from in-depth interview:
“The staff there is fantastic. Very solid.”*

*Quote from in-depth interview:
“Ed Preneta is a joy to work with.”*

Area #2: Funding

Perceived positive: Provides funding to worthy projects

Stakeholders strongly agree that the CT Council on Developmental Disabilities provides funding to very worthy programs and organizations. They appreciate the grant money that the Council spreads throughout the state, and they acknowledge the significant impact that the funding activity has had on improving the lives of people with developmental disabilities in Connecticut.

*Quote from focus group:
“They have an amazing list of accomplishments.”*

*Quote from in-depth interview:
“They have done really good work over the years. Their funding has made a real difference for many people and many organizations. They have had a real impact.”*

*Quote from in-depth interview:
“My only advice to them is that they should just keep doing what they are doing.”*

*Quote from focus group:
“They do an incredible job with the limited resources that they have.”*

*Quote from in-depth interview:
“They are not just talk, like some other organizations. They get things done. They put their money where their mouth is.”*

Perceived positive: Willing to fund pilot projects

Many stakeholders voice their appreciation that the CT CDD is willing to fund pilot projects. They feel the seed money provided by the Council is crucial to getting many new initiatives and pioneering programs off the ground in Connecticut.

Quote from in-depth interview:

“They are an important source of seed money in the state, helping to fund pilot projects that are innovative and important.”

Quote from in-depth interview:

“A lot of times it’s hard to get money for a new and unproven idea. That’s where the DD Council has shown itself, shown that it’s willing to help out in those cases.”

Area #3: Advocacy

Perceived positive: Important advocate for people with developmental disabilities

Many stakeholders view the CT CDD as an effective advocate for people with developmental disabilities in Connecticut. They feel the Council is a respected voice that has clout in political circles in the state. Moreover, they believe the Council is a key influence, furthering the needs and interests of people with developmental disabilities.

Quote from focus group:

“I think they are effective advocates for the interests of disabled people. They are a voice that gets listened to.”

Quote from in-depth interview:

“When I think of the Council I think of them as an advocacy group. They represent the needs of the disabled community.”

Note: this was an area of significant disagreement. About half of stakeholders in the study feel the CT CDD is an affective advocate, while almost an equal amount expressed the opinion that the Council is far too timid and does not speak out strongly enough to be a real advocate. This counterargument is presented in the next section of this report.

Perceived positive: Maintain a singular and sharp focus on the issue

Many stakeholders appreciate the Council's voice in the state and clear focus on people with developmental disabilities. This is important, since, according to the stakeholders, otherwise the issue can get overlooked by political decision makers and the public in general.

Quote from in-depth interview:

"They stay targeted to the issue of developmental disabilities. That's important. Otherwise, it can get lost in the shuffle of other issues."

Quote from in-depth interview:

"They play an important role in an area that might otherwise fall between the cracks."

Quote from in-depth interview:

"They really stay focused on their mission, and that's a good thing."

IID. Connecticut Council on Developmental Disabilities – Negative Perceptions

While most stakeholders are generally positive about the Council, almost all feel there is room for improvement. Some stakeholders expressed the view that there is a great deal of room for improvement, while others believe the Council and its activities need only some adjustment. Below is a listing of constructive criticism that was offered by significant numbers of stakeholders.

Area #1: Weak on advocacy

Perceived negative: Not a true leader – not at the forefront of change

Whether or not the CT CDD is living up to its advocacy potential is a key area of disagreement among study participants. As stated earlier, many expressed the opinion that the Council is serving as an effective advocate for people with developmental disabilities. However, many others believe the Council is a disappointment in this regard, mentioning that the Council is “*too quiet*”, “*too timid*” and “*too cautious*” to be a powerful advocate (quotes from in-depth interviews). They also believe the Council is simply not vocal enough to be a real advocate.

Quote from focus group:

“They have a culture of being safe. ... too safe.”

Quote from in-depth interview:

“They need to stand up and take on a real cause. They’re so timid.”

Quote from in-depth interview:

“They don’t do a good job working with the legislature. They could be a lot more proactive.”

Quote from in-depth interview:

“They could have done more to help high function autistic children. They could have done more using their state contacts to really do something here, but they didn’t.”

A particularly sharp criticism was often voiced regarding the CT CDD as an advocate for *change*. Rather, many stakeholders see the Council as very much behind the curve, staid, and too supportive of the status quo (NOT an advocate for change).

Quote from in-depth interview:

“The DD Council is fearful to be out front. They are not at all aggressive.”

Quote from focus group:

“They are not an advocate of change. For instance, they rarely take a position on legislation. ... And when they do, it’s for the status quo. Like the DMR name change. They just testified against that.”

Quote from focus group:

“They are very cautious. They are unwilling to be a true leader. They should be more bold and provide leadership for systems change, even when it’s not politically correct.”

Some stakeholders hypothesize this may be due to influence from the Governor’s Office, because the Governor has appointment power. These stakeholders believe the Governor’s influence over the CT CDD may keep it more status-quo oriented and less likely to be an advocate for real change.

Quote from focus group:

“They seem to be cautious about challenging things in the state. Maybe that’s because the Governor appoints them.”

Area #2: Structural problems at the CT CDD

Perceived negative: Too rigid

Many stakeholders believe the CT CDD is too rigid in how it operates and how it deals with the community.

- **In its grant distribution:** Its rules for grants are seen as too unyielding, not allowing for enough flexibility. Many stakeholders believe that the CT CDD has an overly narrow focus in what it wants to fund and it will not fund projects that fall outside of those strict parameters.

Quote from in-depth interview:

“They are so inflexible with their granting. You have to fit what they want to fund that year or they really won’t consider you.”

For example, many stakeholders report that the CT CDD only funds agencies/programs that are cross-disability (multiple disabilities). Many stakeholders feel this restriction is unnecessarily rigid.

- *In its general processes*: Another example of its rigidity, according to many stakeholders, is how the Council gets tied up in its own processes. Many believe that *“process bogs down the Council”* (focus group quote). They mention how all members on the Council get equal input, and this striving for consensus slows down the CT CDD in endless meetings and discussions. Many feel that the CT CDD is too concerned with process and not concerned enough with real and meaningful action.

Quote from in-depth interview:

“When I think of them, the first thing I think of is how rigid they are. They are very rigid. They are all about process and procedure.”

Rigidity in grant process

Many complaints regarding the Council’s fixation with process stems from people who have applied for grants. Some expressed the view that the grant process is too complex and seemingly overwhelmed by procedure.

Quote from in-depth interview:

“I was invited to submit a proposal, but it was not a good experience. It was a good bit of work, lots of formalities. I haven’t applied since.”

Quote from in-depth interview:

“They make it difficult to get grants. The way they administer that, it’s just too complex and rigid. It’s cumbersome.”

Perceived negative: Strong focus on people with mental retardation, which forces the CT CDD to ignore other types of developmental disabilities

A few stakeholders expressed the view that the Council should try to broaden its focus and not target so much of its efforts on those with mental retardation. Instead, the Council should direct its energy toward people with other types of developmental disabilities as well.

Quote from in-depth interview

“They have a very narrow focus – mainly on people with mental retardation. They need to look at a broader range of people with developmental disabilities, including those without mental disabilities.”

Perceived negative: More transparency is needed

A large number of stakeholders would like more transparency regarding the Council, including:

- More information on how it makes decisions
- More information on its grant selection process

Quote from in-depth interview

“I’m not clear on their grant selection criteria. How do they decide what to fund? I’d like to know that.”

Quote from in-depth interview

“How do people get put onto the Council? And, how do they get to stay on?”

Stakeholders do not feel the Council is purposely trying to hide anything. Rather, they believe transparency is simply not a priority for the Council. Many stakeholders feel that transparency should be more important to the CT CDD and it should therefore take steps to share more information about its decision making processes with the stakeholder community.

Area #3: Communication challenges

Perceived negative: Aura of superiority

Some stakeholders feel the Council often acts with an aura of superiority. These stakeholders feel that Council members simply act according to their own priorities without demonstrating much interest in consulting with or listening to other activists or group leaders in the state. When the Council communicates with its grant recipients or grant applicants, it appears to communicate with an air of judgment and supremacy.

Quote from focus group:

“They act like, ‘I’ll tell you, you won’t tell us’. They don’t allow for give and take – like it should be between equals.”

Quote from focus group:

“They judge what we are doing. Who the heck are they? We know what we are doing, we understand the needs of the people we serve. We’ve been doing it for years.”

Quote from in-depth interview

“The group [CT CDD] is somewhat exclusive, a small circle. They are not always open to listening and not all people are welcome at the table.”

Perceived negative: Not good at communicating itself and its work

Many stakeholders express the view that the CT CDD keeps too low of a profile. The Council is not seen as communicating in an effective manner to make those in the developmentally disabled community and beyond aware of what it is doing. There is a strong sense in the stakeholder community that the Council should do more to advertise itself and its works.

Quote from focus group:

“They stay below the radar. You only find out what they are doing by accident.”

Quote from in-depth interview:

“They need to do a lot more in getting public awareness, more publicity about who they are and what they are doing.”

Many stakeholders believe that the CT CDD needs higher visibility in political circles, particularly the state legislature.

Quote from focus group:

“Most legislators don’t know about them. And that’s too bad. Maybe they could get more money if more people knew about them.”

One suggestion offered here was to give a public award to legislators who do things in support of people with developmental disabilities. Another idea was for the Council to hold breakfasts for legislators to help them understand their work.

Quote from in-depth interview:

“They need a lot more visibility in the legislature, if they want to be really effective.”

Stakeholders would like to see and hear more about the Council via such things as:

- CT CDD newsletter
- Op eds by Council members in newspapers
- CT CDD press releases
- CT CDD members presenting at more panels
- CT CDD sponsored activities for the interchange of information

Many also feel that the CT CDD’s culture of safety keeps it out of the news – because the Council is hesitant to take strong or controversial positions. Taking on such positions would generate more press and more awareness, according to stakeholders.

Area #4: Dissatisfaction with grant making activities

Perceived negative: Too short term regarding their focus

Many stakeholders voice the opinion that the CT CDD does not stick to an objective for a long enough time. They dislike seeing the Council fund a project for only a year or two, and then stop funding it. They also dislike what they perceive to be continuous change of foci and objectives over the course of the years.

Quote from in-depth interview

“They seem to jump around in their emphasis, in what they fund. They need a more consistent and long term plan.”

Many stakeholders feel this approach makes it difficult for the CT CDD to affect real change. Some stakeholders say that it is often the case that a worthy project gets some financial backing from the Council, but then the financial backing is taken away too soon because the Council moves on to funding something else. As a result, many projects and programs terminate because, according to these stakeholders, the CT CDD does not give them enough time to take root.

Quote from focus group:

“They don’t give enough time in their funding to the organizations, and then the programs fall apart after the funding starts. This can be devastating at the grassroots level.”

Quote from focus group:

“One of the biggest needs, I think, is to help retarded kids in the system. The Council funded this for a while, but then stopped. Why did they stop funding this?”

Quote from in-depth interview:

“Their grant awards are for short periods of time. They often don’t fund things long enough to really get them off and running. It would be beneficial to have longer funding periods.”

Perceived negative: Spread their funding too thin

Most stakeholders acknowledge that the CT CDD’s funding is limited. However, many believe that the CT CDD could do a better job managing their limited funds. Rather than taking their money and spreading it out over many grants, these stakeholders believe their funding could have more impact if it were targeted toward fewer groups and programs – offering a more concentrated bang for the buck.

Quote from in-depth interview:

“The amount of money that they have is relatively small, so that makes it hard for them. And, they spread their money too thin, makes the grant funding less meaningful.”

Part III

State of Developmental Disabilities in Connecticut

IIIA. State of Development Disabilities in Connecticut -- Recent Accomplishments

Stakeholders were in general agreement with what they see as the most positive accomplishments regarding people with developmental disabilities in Connecticut. Listed below are key accomplishments mentioned by a large portion stakeholders (in no special order):

Accomplishment: Greater awareness of the issues

Stakeholders overwhelmingly agree that there is increased and more sophisticated public discourse about the needs and interests of people with developmental disabilities. The issue has become more salient, thanks in large part to advocacy groups and also governmental developments, such as the Supreme Court's Olmstead decision.

Quote from in-depth interview:

"People have a better understanding of developmental disabilities because it's talked about more. For example, people no longer think that disabled people can no longer achieve anything. They see it now, in the media. They can achieve in life."

Quote from in-depth interview:

"There is a lot more recognition of people with developmental disabilities, probably because they are more visible in the community. People see that they are out there living their lives and contributing to society."

Accomplishment: Increasing movement toward community integration for people with developmental disabilities

Stakeholders are unanimous in their excitement over the significant decrease in institutionalization (and increased integration) of people with developmental disabilities in Connecticut. They credit the 1999 Olmstead Decision by the US Supreme Court in helping to energize this development, and they feel Connecticut has made real progress over the past several years in this area.

- It was pointed out, however, that children with developmental disabilities often do not get integrated as well and continue to be institutionalized or "grouped" more often.
- Also, many noted that they look forward to the day when the last big state institution, Southbury Training School, is closed down.

Inclusive instruction is also seen as a key accomplishment in this area.

Quote from in-depth interview:

"There are so many options now for community living here in Connecticut. That's a big accomplishment."

Quote from in-depth interview:

“We have come a long way when it comes to integrating disabled people into the communities – getting them out of big institutions. Thank God for that.”

Many argue that the movement toward community integration has given people with developmental disabilities more control over their own lives and their futures; and made them more likely to serve as their own advocates.

Accomplishment: More sophisticated and active community and advocacy groups

Stakeholders are generally of the opinion that community and advocacy groups who are active on behalf of people with developmental disabilities have truly hit their stride over the past 10 to 15 years, becoming larger and more influential than ever before. Many stakeholders believe that the growth of these advocacy groups has expanded and improved the public dialog about people with developmental disabilities.

Communitas in Manchester was offered as a good example. The ARC of Connecticut was also often mentioned as a key example, as were the subgroups of ARC located in communities around the state.

Other Organizations

Listed below are some other organizations often singled out as doing excellent work in Connecticut for people with developmental disabilities, in addition to the two mentioned above:

- ADAPT
- AJ Pappanikou Center at the UCONN Health Center
- Autism Resource Center
- Association of Retarded Persons
- Connecticut Association for Children with Learning Disabilities
- Connecticut Coalition for Inclusive Education
- Connecticut Council on Developmental Disability (note: most stakeholders refer to it as the “DD Council”)
- Independent living centers
- People First
- Special Olympics
- State of Connecticut Department of Mental Retardation

IIIB. State of Development Disabilities in Connecticut -- Priorities for the Near Future

Despite the significant progress made, stakeholders agree that there is a great deal of work left to be done in Connecticut, as well as nationally, to improve the lives of people with developmental disabilities. Some key priorities for the near future, voiced by a large portion of stakeholders, include:

Priority: Provide services for people with developmental disabilities currently living in community

While stakeholders applaud the movement toward integration in the community, they worry that there are not enough services easily available in communities to support people with developmental disabilities. They specifically see the need for more of the following support services available “in community”:

- Affordable housing
- Appropriate employment opportunities
- Job coaches
- Transportation services – living in a community without accessible transportation services can be very isolating -- particularly in the more rural areas of the state
- Advocates who can help people with developmental disabilities and their families navigate and access the system – getting the benefits and help to which they are entitled
- Trained health care providers with special skills to meet the needs of people with developmental disabilities
- Medicaid for employed people with disabilities who are living in community but often lack adequate health coverage (not working enough to get health coverage)

Quote from in-depth interview:

“We really need to focus on in-home support. That’s the big need for the near future. We’ve seen real progress getting them out of institutions and into the community. But, now they need support in the community – help getting appropriate jobs, help with transportation, the right housing, all that stuff.”

Quote from in-depth interview:

“I have received so many calls about housing [for people with developmental disabilities], how to get it, how to afford it. This is a very big issue and it’s just getting bigger.”

Quote from in-depth interview:

“Transportation is critical. When they live in community, they need a way to get around. In most of the state, the infrastructure just isn’t there.”

Quote from in-depth interview:

“We need to assist towns and communities so that they really know how to integrate disabled people into their town life in its entirety.”

Priority: Support for the entire family

Many stakeholders expressed the view that in the future, family members of people with disabilities should receive more help and support. Being a family member of a person with significant needs often comes with severe emotional, physical and financial strain. These family members need support which, according to many stakeholders, they are not currently getting.

- A few talked about siblings who struggle with the attention that a developmentally disabled sibling receives.
- Others talked about parents and the burdens they bear –especially as they age.

Quote from focus group:

“Family members are often overlooked. They can use support too. The siblings, the parents. Especially aging parents who just can’t do what they used to.”

Priority: More coherence/unity in services

Stakeholders strongly agree that too much fragmentation exists in state services. They feel people with developmental disabilities and their family members become extremely frustrated by the various agencies they need to interact with to get the support they need. A more coherent and unified system would better serve the population.

Quote from focus group:

“Why should families have 12 different case managers, all fighting with each other?”

Quote from focus group:

“Families become so frustrated they say ‘don’t even mention a state agency to me anymore.’”

Priority: Improving the ability to diagnose people with developmental disabilities

Many stakeholders voice concern looking into the future regarding the ability to diagnose people with developmental disabilities. They note that this has been a long term problem in Connecticut and the rest of the nation without any solution in sight. Stakeholders are concerned about youths being misdiagnosed and not receiving the proper treatment. They feel the instances of this may have increased recently with physicians quick to label children ADD (attention deficit disorder) when there may actually be another subtle but more crucial developmental disability involved. Stakeholders are also concerned about the many homeless people and drug addicts in Connecticut who they feel likely have a developmental disability but never are given the opportunity for a proper diagnosis and treatment. These people are seen as often “falling through the cracks.”

Quote from focus group:

“There are so many people out there who are not getting diagnosed properly. How can we get them diagnosed and then give them the help they need? I see that as a big priority for the next decade.”

Priority: Long term care for aging people with developmental disabilities

The American population is aging, as Baby Boomers hit their 60s and improved health care enables people to generally live longer. The same is true for people with developmental disabilities. Many stakeholders are concerned that it will be harder for aging people with developmental disabilities to live independently in their communities. Additional supports will be needed to help these people through their older years, particularly if their parents and siblings are elderly as well.

Quote from focus group:

“The population is aging. As they get older, their need more support. Health care will be an issue, getting around. For many, their parents will be deceased, so there will be a real need there.”

Quote from in-depth interview:

“They are getting older as a population and they are mainly living in community now-a-days. That’s a double whammy. It’s one thing to live in community when you are younger. But as they age, it gets much tougher and the need for community support will be great.”

Priority: Training for professionals – keep the field appealing

Stakeholders are also concerned that young people may be less likely to be interested in joining the field of developmental disabilities, either as:

- Health care providers (at all levels)
- Home care assistants
- Social workers
- Advocates

Quote from focus group:

“We need to keep quality people in the profession. And, we need to make sure we keep a steady stream of quality people coming in.”

Stakeholders want there to be steps in place to ensure the field remains enticing and brings in competent and compassionate people. Some thoughts voiced:

- Keep salaries competitive
- Launch communications campaigns to entice young people into the profession (as has been done in the past for fields such as teaching, nursing)

Priority: More support for community advocacy groups

Stakeholders strongly believe that community advocacy groups play an essential role that state agencies or larger groups cannot – and that role is advocating for real change in the system. Even the state agency stakeholders who participated in the study generally agreed that community advocacy groups are critical to the process – able to push for change far more forcefully than the state agencies can.

Quote from focus group:

“The community groups are always the ones that lead the charge.”

Quote from focus group:

“Advocacy groups are the bees that buzz, keeping the state honest.”

Going forward, stakeholders want to be sure that community groups get the support that they need to stay active and viable. The support they view as most critical fall into two categories:

- Financial assistance
- Expertise
 - In grant writing, budgeting, communications, lobbying, etc.

Priority: Synthesis of research and resources

Many stakeholders see a lot of research and activity taking place, but no synthesis of what is learned from all of it. They would appreciate a program that could bring this research and activity together into one user-friendly informational network.

Substantive areas to include:

- What have we learned about the most effective ways to help people with developmental disabilities? For example:
 - What community programs work best and why?
 - What approaches to family support work best and why?

As mentioned above, tactical areas to include would be:

- Grant writing resources
- Budgeting and accounting
- Communications and outreach
- Lobbying

Quote from in-depth interview:

“We need someone to bring all the learning together. To make sense of the big picture ... to connect the dots.”

Quote from in-depth interview:

“It would be great if someone would do a comprehensive, historical analysis of what initiatives have been taken and what impact they have had, or not had. We can’t learn from the past without taking a smart look at it.”

Part IV
Conclusions and Recommendations

IV. Conclusions and Recommendations

The research offers several insights for the Council as it plans for the future:

First, the Council should be pleased about the positive feedback that it received. Most stakeholders have a positive view of the Council and its activities. Positive themes that were most commonly expressed by stakeholders:

- Council membership and staff
 - Respect for individual Council members.
 - Applaud the inclusion of people with developmental disabilities on the Council.
 - Appreciate the diverse backgrounds of Council members.
 - Admire the skill, professionalism and friendliness of CT CDD staff.
- Funding
 - Believe the Council funds worthy projects, which significantly improve the lives of people with developmental disabilities.
 - Appreciate that the Council funds pilot projects – providing valuable seed money to get programs and ideas off the ground.
- Advocacy
 - View the CT CDD as an effective advocate for people with developmental disabilities.
 - Admire the sharp focus that the CT CDD maintains on the issue of developmental disabilities.

Constructive Criticism

However, there is clearly room for improvement, according to stakeholders. Though generally positive, stakeholders were often only *mildly* positive about the Council. Further, a small but noteworthy minority of stakeholders (about 1 in 7) expressed a negative view of the CT CDD. Constructive criticism offered included:

- Weak on advocacy
 - Many feel the Council is timid and not as strong of an advocate as it could or should be.
 - The Council is seen by many as not being at the forefront of change.

Suggestion: the Council should conduct an internal audit to see where it has acted as a forceful advocate for change and where it may have shied away from advocacy. Did it miss any opportunities? If so, why? What held it back? How can the Council learn from these incidences?

The Council should try to be more vocal on issues which it feels are important. It should use the media and other communications sources whenever possible to showcase its advocacy.

In its communications with stakeholders, the Council should emphasize its advocacy activities, since this message is not getting out effectively to many in the field.

- Structural problems – the CT CDD is seen as:
 - Too rigid in its organization.
 - Too strict in its grant making.
 - Not transparent enough.

Suggestion: the Council should conduct an internal review of its procedures – are there any areas where more flexibility can be introduced? Can the grant application procedure be more user-friendly and flexible?

The Council should consider ways of opening up its procedures – inviting stakeholders to meetings; putting even more details up on its website regarding CT CDD activities and decision making; and any other reasonable steps to improve transparency.

- Communication challenges
 - The CT CDD often conveys a feeling of superiority when it interacts with others.
 - The CT CDD does not communicate enough to the stakeholder community

Suggestion: the Council should discuss internally the issue of interface with stakeholders, and explore why some stakeholders might feel the Council acts with an air of superiority? Protocols can be written to help members of the Council improve their interactions with stakeholders – a tip sheet on how to best handle meetings and phone calls with stakeholders, being sure to ask for input and outside perspectives, etc.

The Council should consider ways to communicate more often and more effectively with the stakeholder community:

- *Newsletter (e-mail and paper version)*
- *More interactive website*
- *Regional meetings or social get-togethers (breakfasts, etc.) with stakeholders*
- *Quarterly call-in conference calls – question and answer sessions*

- Dissatisfaction with grant making activities
 - The CT CDD is seen as too short-term in its funding.
 - The CT CDD is seen as spreading its funding too thin.

Suggestion: the Council should conduct an internal review of its grant making priorities. Are there instances where longer term funding is appropriate? Otherwise, the Council should create an argument for why they tend toward a “start up” approach – and work that into communications materials so stakeholders can begin to understand the rationale behind the shorter term funding.

Perhaps the Council can do more to teach grantee how to continue their funding via grant applications to other organizations, ways to raise money via user fees, etc. This way, organizations won’t feel as if they were left with nothing when their CT CDD grant ends.

Areas for Future Funding and Support

Based upon the priorities for the future expressed by stakeholders, following are some key funding priorities for the Council to consider for the near future:

- In-community support for people with developmental disabilities. Key areas in which to focus:
 - Housing
 - Jobs
 - Transportation
 - Health care
 - Special assistance for aging individuals
- Support for family members of people with developmental disabilities.
- Support for efforts that simplify and add coherence to the array of services available to people with developmental disabilities – some sort of central clearing house to serve as a middle man between the public service bureaucracy and people with developmental disabilities.
- Support for improved diagnosis – especially for marginalized people who often fall in between the cracks.
- Support for recruitment and training of future professionals and caregivers in this field.

- Support for community advocacy groups to continue their advocacy work
 - Financial support
 - Expertise support
- Support for a comprehensive review of research conducted to date – a meta-analysis of what has been learned