



# A Focus Group Discussion Regarding the RI Developmental Disabilities Council's Decision to Incorporate as a Non-Profit Organization

Focus Group Conducted on: April 16, 2009

By

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On April 16, 2009 nine members of the community representing advocates, people with developmental disabilities, MHRH and DOE state workers, our sister agencies (Sherlock Center and RI Disability Law Center) family members and community provider organizations, as well as staff, consultants and members of the Rhode Island Developmental Disability Council (RIDDC) attended a meeting to discuss the advantages and disadvantages of the federal and state non-profit status of the RIDDC. (See attached copy of the Focus Group Script.) The information received at this meeting will be presented at the DD Council meeting on June 17, 2009.

Robert Marshall, RIDDC Consultant, welcomed everyone to the meeting, distributed copies of the agenda and other informational materials about the Council, and had individuals introduce themselves.

Christine Singelton, Chairperson of the Systems Advocacy Committee of the RIDDC, provided a brief overview on the federal requirements and responsibilities of the RIDDC.

A history of the RIDDC and timeline of events leading up to the decision to pursue non-profit status was presented by Mary Okero, Executive Director of RIDDC. Developmental Disabilities Councils were formed nationwide by federal legislation in the early 1970's, council members to be appointed by each state governor, and federal monies for programs to be administered by state government.

In the 2008 state budget, the Rhode Island House Finance Committee proposed that advocacy agencies, including the RIDDC, consolidate as a way to save money. In response, the Governor in his 2009 budget proposal consolidated three advocacy agencies (RIDDC, Governor's Commission on Disability, Commission on Deaf and Hard of Hearing) into the Department of Elderly Affairs and renamed the Department calling it the Department of Elderly Affairs and Advocacy. The RIDDC, by federal law, cannot be consolidated with any agency that provides services to persons with developmental disabilities nor can the federal monies for the DD Council be co-mingled, saved or appropriated to or by any other agency. When the Legislature realized this, a floor amendment was made

to the 2009 budget directing the RIDDC to pursue non-profit status.

Sue Babin, RIDDC Consultant, discussed the importance and purpose of this Focus Group. The Council is using this group and its interaction as a way to gain public information and input about a specific or focused issue – in this case, it is the decision of the Council to become a private, non-profit corporation.

Ms. Babin then facilitated an open discussion with participants on the general advantages and disadvantages of why organizations become non-profit corporations and to obtain their ideas on the advantages and potential challenges the Council may face as a non-profit corporation. The following is a summary of the questions asked of participants and their individual comments and ideas.

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**Question: What reasons do people decide to form non-profits? There are now 7,500 non-profits in the state of Rhode Island. Why do they decide to apply for 501(c)(3) status?**

One respondent mentioned to have tax-exempt status.

Most of the respondents agreed that “a lot more autonomy” is gained through non-profit status.

A discussion followed that groups organize for a “specific purpose” or “mission” about a community need that they were “passionate about.”

It was mentioned that groups who enjoyed non-profit status had greater budget control than when under “state administration.”

The ability to broaden fund raising through grant writing, matching funds and donations was also discussed.

In the specific case of the RIDDC, it was stated that as a non-profit the DD Council would not have to comply with “state hierarchy.”

Questions raised regarding this status for RIDDC were largely administrative in nature rather than mission related. Respondents were told that the Governor would still appoint Council members, reassured that no federal funding would be lost, and that the federal monies would be administered by a state entity (University of Rhode Island).

**Question: What are the advantages of non-profit status? What does a non-profit get you that you cannot have as a state agency?**

The respondents discussed both administrative and mission-related advantages. Advantages discussed were:

- The ability to “create your own rules and by-laws” and the “flexibility to make your own decisions.”
- The “flexibility to move quickly” on administrative matters.
- The autonomy to form “linkages or connections” with other agencies.
- The ability to have or “find more funding sources” and get “matching funds.”
- “Creation of your own mission statement.”
- Payments to vendors can be made “faster.”
- There would be no state involvement in hiring and budgeting would not be questioned.

A question regarding whether any other DD Council in the country was a non-profit was asked. A discussion regarding the DD Councils in Florida and Montana, which are 501(c)(3)s, ensued. It was explained that the federal government does not want this to become a trend and likes the state “oversight.” It was also noted that these two DD Councils found their new status to be beneficial.

A respondent questioned, “What do you get from the state that is good?” It was answered that an administrator who does the federal reporting was excellent. It was also noted that the DD Council enjoyed greater support from the state years ago before the current multi-year budget crisis.

**Question: What are some potential challenges or risks that the Council may face as a non-profit?**

It was stressed that the Council must make sure that the Legislature understands this move to non-profit status.

The aspect of “learn as you go” was also mentioned. A discussion followed that there were many agencies (an example given was of PAL) which started as grassroots first and then became non-profits. It was noted that these agencies would be “of help” if the DD Council applied and became a non-profit.

A discussion on whether there would be “any bad PR here.” Although there was some resistance to the decision to apply, it was stated that the Governor’s office has “signed off” on pursuing non-profit status.

The prospect of “how much work” it takes to become a non-profit was cited.

It was noted that non-profits must be constantly vigilant of fiscal mismanagement. They would now have fiduciary responsibility which would involve audits and IRS reporting responsibilities.

A respondent cited a newspaper article which estimated that there would be 1/4 less Rhode Island non-profits in the next ten years. In response to this concern, it was stated that the DD Council is federally mandated, has federal funds for its budget, and, unless there was a change in the federal law, the DD Council should be secure.

**Question: What are the disadvantages of becoming a non-profit?** Respondents cited the following as disadvantages:

The need for “reporting requirements.”

The need for “transparency.”

The “learning curve.”

There might be a “loss of access” to state government.

A “perceived loss of credibility” after leaving state government was mentioned and the necessity to keep established ties and networks to the legislature and state offices as strong as they are at this time was stressed.

The need to “chase funds” and the difficulty of finding sources of funding was mentioned. There was a brief discussion regarding the disadvantages of state billing and purchasing regulations versus the difficulty of “finding funds.”

**Question: What new possibilities or opportunities does a non-profit status present for the Council?**

Other forms of fund raising were discussed, as well as establishing an endowment fund. It was noted that the Board members were the first “rain makers” in any organization. As a non-profit, the DD Council would be able to accept grants from companies and foundations.

One respondent interjected that a smooth transition from state entity to non-profit as the RIDDC’s first priority, not fund raising.

The ability to have a greater visibility within the community (separate from the state) was mentioned.

An expansion of the mission statement could occur. The DD Council could “craft its own face” – the public could readily distinguish the difference between the DD Council and the “Governor’s Council.” It would be an opportunity to make the community more knowledgeable about the DD Council.

Relationships with other non-profits and legislators may actually be strengthened.

The DD Council would enjoy increased freedom and ability to advocate for and organize other groups which are under-represented. An example of this would be those who may become homeless.

**Question: Are there any other comments or concerns you have regarding the DD Council’s application for non-profit status?**

It was noted that the DD Council needed to carefully plan how they were going to “get this [the move to non-profit status] message out.”

Regarding more questions on how Florida and Montana’s DD Councils “liked being a non-profit,” it was stated that Council members would be attending at DD Conference in June and would gather more information from these two Councils.

Questioned by a respondent why “they” want a non-profit, members of the RIDDC noted the prohibitive time and mechanism constraints as a state entity, as well as the restrictions in lobbying and advocacy.

Respondents cautioned RIDDC to make sure “all the ducks were in a row” for applying for non-profit status.

Questioned by a respondent on “full-time” versus “part-time” staffing, there can be “part-time” staffing as a non-profit, (this is more difficult as a state entity.)

Questioned by a respondent on federal lobbying, it was stated that there cannot be federal lobbying at this time because it is only one-source funding—which is federal. It was noted that if the Council becomes non-profit, the RIDDC would have the ability to lobby federally with outside monies.

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Mr. Marshall thanked the participants for taking the time to come to the meeting to provide their feedback, insights and comments about the Council’s action to become a non-profit corporation.

Members and staff of the RIDDC came away from the focus group with a clearer understanding of the many opportunities and potential challenges involved in a transition from a state entity to a non-profit, the need to keep strong relationships with the state legislature, state government, and other non-profits, as well as the need to have a strong administrative team.

Conversely, Council members were encouraged by the enthusiasm and concrete ideas exhibited by the focus group respondents that the RIDDC could become more effective in their mission, their advocacy and lobbying, and their ability to pursue outside funding sources.

## Appendix 1 -- Focus Group Script

### **Welcome and Introductions**

(Bob Marshall and Sue Babin)

### **Brief Comments on the Federal Requirements and Responsibilities of RIDDC**

(Christine Singleton, DD Council Executive Committee Member)

To convene meetings of the 24 member Council and additional Associate members as a planning and advisory body and to coordinate the work of the Council through its standing committees: *Systems Advocacy and Individual Family and Advocacy*.

To promote implementation of a wide array of options for services/supports to assist people with developmental disabilities to achieve self-determination and maximize their independence and quality of life in Rhode Island.

To identify ways to improve services for individuals and their families and to identify barriers and needs for additional services. This information is submitted to the federal government in the form of the Council's State Plan.

To work collaboratively with other advocacy organizations, community and state agencies, and other interested individuals in implementing the mission and goals of the Council.

### **Purpose of the Meeting**

(Sue Babin)

To solicit public input from Focus Group participants on the decision of the RIDDC to change the status of the Council from a state agency to a non-profit corporation.

To record the comments, ideas and feedback of participants.

To present a copy of this recorded information to Mary Okero, Executive Director, Executive Committee and all Council members at the next Council meeting in June 2009.

### **Timeline of Major Steps leading up to the decision to become a non-profit 501 ( c ) ( 3 )**

(Mary Okero, RIDDC Executive Director )

June 2007 House Finance Committee directs Governor to form an "*Advocacy Dept*" comprised of the DDC, Governor's Commission on Disabilities, Commission on Deaf and Hard of Hearing, Child Advocate's Office and Mental Health Advocates Office. This would move the Council from the Executive Branch of state government to a single state agency. Each of these 5 agencies state opposition to this consolidation.

October 2007 Hearing at Budget Office for all 5 agencies to testify on the consolidation. Plan of Governor is to create a "*Division of Advocacy*" within Department of Elderly Affairs.

January 2008 Gov's budget is submitted...change now stipulates only 3 of the 5 agencies will be included within Elderly Affairs (removing Mental Health Advocate and Child Advocate's Office).

January 2008 DDC Associate Director position frozen for 4 months...Request to fill position goes before State Emergency Hiring Council of 8 department directors who direct the Council to re-write the job description to be more generic.

February 2008 Letter sent to Governor Carcieri from Mary Okero stating Council's opposition to proposed budget article to move RIDDC to DEA as a violation of the governing federal law related to funding and authority of the Council.

March 2008 Council members vote to become a non-profit to increase flexibility in decision making, hiring capacity, and opportunity to eliminate bureaucratic processes inherent in state system requirements, as well as to become eligible to apply for funding for private and governmental grants for creative projects to support the mission and goals of the Council. The Council will also have the opportunity to accept contributions, donations, raise other funds and in-kind resources that are tax-deductible on taxpayer's income tax returns, and to receive tax exemptions at state and federal level.

June 2008 Advocates ask legislators to not approve the legislation to consolidate and leave each agency as an individual entity. House Finance votes on amended bill and removes all advocacy agencies EXCEPT DDC and leaves the Council within DEA.

July 1 2008 Legislation submitted and passed that DDC will move administratively from the Executive Branch of state government to URI and detailing the conversion to a private non-profit entity.

January 2009 Council budget now included within URI, the new Designated State Agency to draw down the federal funds for the Council. Articles of incorporation for the Council have been filed with Secretary of State's Office. Next step is to complete the 501 ( c ) ( 3 ) application to the IRS.

### **Facilitated Discussion with Participants**

(Sue Babin)

The general advantages and disadvantages of why organizations become non-profit corporations... to obtain participants ideas on the advantages and potential challenges the Council may face as a non-profit corporation.

#### Importance of Focus Groups...

Focus groups were originally called "focused interviews" or "group depth interviews". The technique was developed after World War II to evaluate audience response to radio programs. Since then social scientists and program evaluators have found focus groups to be useful in understanding how or why people hold certain beliefs about a topic or program of interest.

The Council is using this group and its interaction as a way to gain public information and input about a specific or focused issue...in this case it is the decision of the Council to become a private, non-profit corporation. The intent is to create an inviting and permissive environment that encourages different perceptions and points of view that are welcomed by the Council.

#### Questions to facilitate this discussion....

What are some of the reasons why entities want to become a non-profit corporation?

What does a nonprofit status get you that you cannot have as a state agency? (*What are the major advantages of being a non-profit? What limitations/constraints exist for a state agency?*)

What are some of the challenges/risks that the Council may face as a non-profit corporation? (*What could be some problems or issues?*)

What new possibilities/opportunities does a non-profit status present for the Council? (*What creative avenues could this open up for the Council?*)

Any other comments/feedback???

**Thank you!!!**

## Appendix 1 -- Focus Group Participant List

<b>Name</b>	<b>Constituency</b>
Anne Mulready	RI Disability Law Center
Anne Frank	PAL (Advocacy Organization)
Deb Kney	Advocates in Action
Janet Iovine	Sherlock Center
Kevin McHale	Self Advocate
Maria Velasquez	RI Department of Education
Rebecca Beaton	Self Advocate
Rory Carmody	Provider
Susan Hayward	RI Department of Mental Health, Retardation & Hospitals - Division of Developmental Disabilities