

NOVEMBER 20, 2014



**FINAL REPORT TO THE  
NC COUNCIL ON  
DEVELOPMENTAL DISABILITIES**

**S. BARTON CUTTER, JONATHAN ELLIS, MONICA J. FOSTER & MATTHEW POTTER**

N.C. ADVOCACY AMBASSADOR INITIATIVE IS A PROJECT FUNDED BY THE N.C. COUNCIL ON DEVELOPMENTAL DISABILITIES  
& ADMINISTERED BY MICHAEL MAYER, COMMUNITY RESOURCES ALLIANCE (CRA)

## Table of Contents

<b>Authors Page</b>	<b>2</b>
<b>Executive Summary</b>	<b>3</b>
<b>Section I: Historical Context and Stakeholder Perspectives</b>	<b>7</b>
<b>Section II: Group Survey Analysis</b>	<b>13</b>
<b>Section III: Individual Survey Analysis</b>	<b>21</b>
<b>Section IV: Recommendations for a Path Forward</b>	<b>29</b>
<b>Appendices</b>	
<b>A. 1 National Picture Relative to N.C.</b>	<b>35</b>
<b>A. 2 Stakeholder Engagement Group Priorities</b>	<b>52</b>
<b>A. 3 Stakeholder Interview Questions</b>	<b>53</b>
<b>A. 4 Individual Survey Questions</b>	<b>54</b>
<b>A. 5 Organizational Survey Questions</b>	<b>62</b>
<b>A. 6 Advocacy Ambassador Regional Map</b>	<b>68</b>
<b>A. 7 Advocacy Ambassador Facebook Page</b>	<b>69</b>
<b>A. 8 Advocacy Ambassador Business Cards</b>	<b>70</b>
<b>A. 9 Advocacy Ambassador Brochure</b>	<b>71</b>
<b>A. 10 Advocacy Ambassador Biographies</b>	<b>73</b>

## Authors Page

S. Barton Cutter  
(919) 741-4876  
[ambassador.barton@gmail.com](mailto:ambassador.barton@gmail.com)  
[www.cuttersedgeconsulting.com](http://www.cuttersedgeconsulting.com)

Jonathan Ellis  
(910) 231-4350  
[ambassador.jonathan@gmail.com](mailto:ambassador.jonathan@gmail.com)

Monica J. Foster  
(704) 490-2063  
[ambassador.monica13@gmail.com](mailto:ambassador.monica13@gmail.com)  
[www.butterflywheel.com](http://www.butterflywheel.com)

Matthew Potter  
(336) 409-3096  
[ambassador.matt13@gmail.com](mailto:ambassador.matt13@gmail.com)

## EXECUTIVE SUMMARY

The N.C. Advocacy Ambassadors, in conjunction with the Community Resource Alliance (CRA), were charged with assessing the current state of self-advocacy within North Carolina under a 12 month grant from the North Carolina Council on Developmental Disabilities (NCCDD). The Ambassadors, individuals who themselves have disabilities, were recruited to reach out as a team to existing grass roots advocacy organizations across the state and determine the elements needed to ensure a robust self-advocacy movement in North Carolina.

The immediate goal of the N.C. Advocacy Ambassador Initiative team was to identify the specific strengths and weaknesses of the existing movement and to provide recommendations for rectifying weaknesses while bolstering existing strengths.

Two separate surveys and extensive stakeholder interviews were used to gather information. Results of the survey and interview process revealed that the current state of self-advocacy is tenuous at best and that major areas of concern need to be addressed to build a functional self-advocacy movement. Major emphasis needs to be placed on the following areas:

- **Education and training** in current advocacy issues, advocacy skills, group dynamics, collaboration, and communication
- **Technical assistance** for existing and emerging self-advocacy groups towards more regular, well-attended, well-governed meetings and connecting them with others and to address the other needs identified by the groups, such as using technology to support their efforts,
- **Identification of self-advocates with leadership potential** and the provision of training for them
- **Support** to state agencies and provider organizations to ensure access to processes and feedback that are accessible and self-advocate-oriented

### Stakeholder Perspectives (Section I)

Stakeholders were interviewed regarding their feelings about the status of self-advocacy in North Carolina. Stakeholders interviewed ranged from self-advocates, current and former heads of advocacy (including self-advocacy) groups,

representatives of provider organizations, disability rights advocates and attorneys, and state employees. The interviewees were guaranteed anonymity and thus, gave the most candid answers possible regarding the problems they saw facing self-advocacy.

The consensus among stakeholders is that the state self-advocacy movement is dysfunctional and ineffective due to:

- In-fighting
- Conflicting personal agendas
- Lack of a cohesive vision
- Lack of resources and support, both monetary and organizational

The picture of self-advocacy in North Carolina from the perspective of stakeholders is, at present, a dire one. However, stakeholders were united in the view that the situation could be vastly improved with adequate support provided by the right team.

### **Group Survey Analysis (Section II)**

During the initial phase of the Advocacy Ambassador Initiative, the Ambassadors encountered major hurdles in identifying pockets of active advocacy, both in group form and among unaffiliated individuals, despite reports to the contrary. Initially, the Advocacy Ambassadors began their exploration using the most recent membership lists from the Association of Self-Advocates of North Carolina. Yet, only a very small sample of member groups remained active in the wake of the only statewide self-advocacy organization's decline in 2009.

The responding organizations, although few, admitted needing and wanting outside assistance to:

- Continue a self-advocacy, person-first focus
- Grow their membership
- Remain viable as an organization

The low response speaks to both the low number of existing organizations and the poor communication, engagement, and collaboration among those that do exist.

The few responding leaders of these organizations generally believe they are working with a clear vision and mission and that the membership of their organization clearly understands their purpose for existing as a self-advocacy organization. However, if perceptions aligned with the current environment, the status of self-advocacy groups would be substantially better, demonstrating major outcomes for their constituencies. In short, the outcomes do not match the beliefs of the responding leaders.

### **Individual Survey Analysis (Section III)**

Of the 172,000 people with IDD in the state, the Ambassadors were able to make contact with approximately 500 self-advocates, nearly 300 of whom were communicated with directly by the AAI team, but of which only seventy-six people responded to the individual survey despite the well-coordinated attempt to disseminate, publicize, and encourage candid responses.

Such a low response rate does not allow for reliable and comprehensive patterns to be determined. The responses *do* reflect, however, a number of important issues:

- ***Lack of understanding*** of pertinent issues
- ***Unwillingness to share*** candid opinions and sentiments (suspected to be because of perceived pressure or fear of retribution)
- The need for ***greater capacity to define personal support needs*** among members of advocacy groups

### **Path Forward (Section IV)**

To address these current realities, the Advocacy Ambassador Initiative team feels that a multi-dimensional approach to strengthen and foster collaboration among willing and interested parties is required to ensure that the state self-advocacy movement becomes both unified and effective in its mission and objectives. This includes direct collaboration with allies, such as Disability Rights North Carolina. These efforts will also include the development of a self-sustaining business model to facilitate these goals on a long-term basis.

Initially, a strong emphasis will be placed on forging a cohesive infrastructure to:

- ***Strengthen and expand*** self-advocacy groups

- ***Build communication*** between groups across the state
- ***Develop collaboration*** among self-advocate leaders
- ***Facilitate self-sufficiency*** of the supports to sustain these efforts

To this end, our recommendations are that action be taken in four areas of most immediate need:

- ***Technical assistance***
- ***Communication and technology***
- ***Leadership development and education***
- ***Developing and implementing a working “business” model to continue to provide the above services and supports***

## **Section I: Historical Contexts and Stakeholder Perspectives**

### **Introduction**

The N.C. Advocacy Ambassador Initiative team asked 13 individuals (hereafter referred to as “respondents”) the same set of questions regarding their feelings on the state of advocacy in North Carolina. The respondents were guaranteed anonymity in their responses, and thus gave the most candid answers possible regarding the problems facing advocacy for people with disabilities. Respondents ranged from self-advocates with their own businesses to former heads of advocacy groups to disability rights attorneys to even state employees.

While the types of experiences and differences in vantage point were vast, the themes, issues, and solutions that emerged were generally very consistent. This is both distressing and encouraging; the picture of advocacy in North Carolina as of the time of this report is a dire one. However, it is clear based on what respondents told us that a better future is definitely possible.

### **What Does an Effective, Statewide Advocacy Group Look Like?**

Common themes for this section included an emphasis on things being run by advocates for advocates. While allies and others would be an important part of the process, their main function should be that of support.

Types of support frequently mentioned include financial supports, transportation support, and of course moral support. The establishment of an advocacy group across the state would facilitate the ability of individual groups to flourish (for example, specific disability sub-groups having places and ways to congregate about issues that are important to them) and it would discourage isolation and the jockeying for power between specific local or regional groups.

Rather, these individual groups would exist but also collaborate and support one another, to allow for simultaneous self-sufficiency and interdependence, and not strictly focus on “independence” from all other groups.

Other common themes include the need for frequent and accurate communication in ways that self-advocates could access and understand, the use of technology to facilitate communication, and the need for clearly defined visions, missions, and goals for advocacy groups and the means to attain these goals.

### **Thoughts on the Current State of Self-Advocacy in N.C.**

The responses we obtained were rather universal regarding the current state of self-advocacy in North Carolina.

While some respondents mentioned glimmers of effective self-advocacy through organizations such as The Arc, in general the descriptions of the current status were dismal.

Frequent terms used included “splintered”, “no collaboration”, “lack of support”, and the potential for the image of a phoenix rising from the ashes. Several respondents hadn’t heard of any ongoing efforts whatsoever, which is rather telling by itself and speaks to the “tenuous at best” picture painted by all 13 of our extremely knowledgeable respondents.

While many mentioned no support from providers and allies, others also mentioned the concerning issue of providers having “taken over” advocacy groups and co-opting their agendas for their own purposes.

### **Current Rating of Self-Advocacy in N.C. from 1-10**

Aggregating all of the 13 respondents, the average number for the current state of advocacy in N.C. was 3.3. The lowest number given was a 0, and the highest given was a 6. The majority of respondents rated the situation at a 3 or a 4. Obviously this indicates an incredibly fractured system of self-advocacy at best, and an utterly ineffectual and dysfunctional system at worst.

Unfortunately, the worst perspective was the one most frequently held. Clearly, interventions and assistance are needed.

## **Thoughts on Some of the Biggest Problems Currently Facing the Self-Advocacy Movement in N.C.**

Common themes in this section are very apparent. Discussions of lack of support, both financial and otherwise, were extremely common. Some talked about no support whatsoever, which left self-advocacy groups on their own in an environment in which they are unable to succeed.

Meanwhile, some respondents noted that, contrary to a lack of help, unfortunately and too often, those who try to help self-advocacy groups sometimes overstepped boundaries and pressed their own agendas on the groups they claimed to be assisting.

Transportation was another frequently mentioned barrier to effective self-advocacy.

Finally, a lack of cohesion is clearly a problem, and it is mentioned in both the context of egos and/or overpowering personalities among self-advocates, as well as a demonstrated lack of understanding about what is required for an effective self-advocacy group/effort.

## **Thoughts on Possible Solutions to the Problems with Self-Advocacy in N.C.**

In addition to the above comments, common responses in this section included assistance to help repair wounded relationships, support to connect the smaller groups together, and the use of technology as a means to overcome certain issues associated with transportation and a general lack of knowledge of the issues and how those issues affected individual self-advocates and the community as a whole.

Another common theme is the acknowledgment that individual agendas, and sometimes those issues unique to certain types of disabilities, are bound to exist and are essentially unavoidable, but that such things are only a problem when they overtake the collective agenda and goals that will benefit all.

It can be inferred by many of these suggestions (and was directly stated by some) that the creation of a body to advise, train, monitor, and link self-advocacy groups is very much needed and would be very much welcomed by those who have invested in the development of self-advocacy.

A “self-advocacy clearinghouse” is one possible option that was mentioned by several participants. It is important to remember, however, that steps would need to be taken to ensure that self-advocacy movements would remain “by self-advocates, for self-advocates”, and that guidance and the training would not become overbearing and not usurp individual organizational goals nor creativity from local or regional self-advocacy groups.

### **What is the Ideal and Attainable Rating of Self-Advocacy in N.C. (from 1-10)?**

The majority of respondents answered that the movement has the capability of being a 9 or 10 on this scale with the right supports in place.

The respondents who chose 9 were clear to indicate that the reason they did not say 10 was due to their desire to never suggest that there isn't room for improvement. Regardless, the potential increase was three times the current average score.

While a few respondents rated it as a 6 or 7, they were clear to indicate that that was meant to be more of a pragmatic answer with regards to what they actually believed *would* happen without concerted efforts such as the Advocacy Ambassador initiative, rather than a belief that things couldn't be better than that.

This is largely due to the need to manage many complex factors, including personalities/power struggles, funding, and the like. It is our belief that with proper interventions and activities, “the score” in the next couple of years could get up to an 8 or a 9.

## **Thoughts on the Most Necessary Efforts/Resources to Bridge the Gap Between Current and Ideal Scores**

Once again, it was the consistency among the multiple themes that emerged was notable. The most frequently mentioned resource mentioned as being needed was people who were capable and trustworthy.

**Many respondents mentioned that the self-advocacy movement needs focused, dedicated leaders who will simultaneously take responsibility and maintain humility while being able to skillfully manage historically strong personalities to prevent a repeat of past efforts.**

There were multiple inferences that people who are effective at keeping strong personalities and egos in check would be a highly valued resource. This is both a problem and a solution that is agreed upon by the Advocacy Ambassador Initiative team. Further, the solution cannot be “Raleigh Centric” as the need is literally in every corner of the state. Therefore, the solution needs to be statewide.

Other resources needed included technology (especially for improved communication), funds to cover the costs associated with managing such an effort (such as, training, communication), transportation, and “effective support systems”. The need for intellectually accessible and effective training materials and education was frequently mentioned.

## **Closing General Thoughts from Interviewees**

The main themes in the closing thoughts were messages of support and approval of the Advocacy Ambassador Initiative, and the **strong belief among the respondents that efforts to promote self-advocacy need to continue if there is any hope for truly effective self-advocacy in NC.**

We have received strong messages of support for advancing self-advocacy from both individuals and advocacy organizations, such as The Arc, Disability Rights North Carolina, and North Carolina Partners in Policymaking, as well as other policy makers and implementers (such as LME/MCO’s), and some of the most progressive providers.

The only other common theme in the respondent's closing messages was that those **trying to repair advocacy in N.C. will need to be very sophisticated in the management of personalities and in conflict resolutions** – and they must be careful to avoid repeating the historic problems mentioned above.

## **Section II: Group Survey Analysis**

### **Context**

The relationship between support staff and people with disabilities is typically viewed as one involving unequal power – with the staff having more power than the person with the disability. This can, and unfortunately frequently does, result in fear. That fear, at its core, comes from the invaluable nature of support staff. People with disabilities often fear the idea of saying something negative about supports that could jeopardize their supports, because without the supports, the people with disabilities feel helpless.

As a result, whether this fear is based in reality or not, the idea of being surveyed about quality of life, especially when some of the questions relate to supports, can be an extremely intimidating and frightening proposition for any person with a disability reliant on such supports.

Consequently, this fear often translates to self-advocacy groups which do not like being surveyed or questioned about their work for fear of revealing areas of weakness and the fear of having the group taken over by service providers who are not self-advocates themselves.

Surveying self-advocacy organizations proved to be a difficult task, but a small sample did respond to our effort. The surveys revealed that group leaders are hesitant to be examined, and yet do desire some support to grow and build long-term sustainability once they recognize a friendly, self-advocacy ally rather than an entity offering what they perceive as controlling direction.

### **Dissemination Process and Challenges**

During the initial phase of the Advocacy Ambassador Initiative, the Advocacy Ambassadors encountered major hurdles identifying pockets of active self-advocacy, both in group form and among unaffiliated individuals.

Initially, the Advocacy Ambassadors began their exploration using the most recent membership lists from the Association of Self-Advocates of North Carolina. Yet, as one might imagine, the information received from an organization that has been

effectively inactive since late 2009 was extremely outdated, and only a small sample of member groups remained active in the wake of the lead organization's decline.

Once this list of groups and members was exhausted as a source of potential survey participants, it became incumbent upon the Advocacy Ambassadors to utilize their personal and professional networks to uncover additional advocacy groups and individual advocates that existed outside of the old Association's membership.

Since this effort only yielded four additional self-advocacy organizations that are currently active being identified for survey purposes, the total study sample of active groups surveyed was far smaller than the 20-30 that had been anticipated.

In surveying those remaining, active groups, there were a variety of barriers encountered in gathering quality information:

- Out-of-date or incorrect group information
- Polarization and a hesitation to collaborate, especially among a few self-advocates that have historically been very active
- Challenges related to survey accessibility regarding the design of the questions
- Lack of trust among self-advocates, i.e. a fear of the misuse of information
- The attempt to skew the data by some family members and/or providers

## **Analysis of Findings**

### **Clearly Defined Vision & Mission**

Of the self-advocacy organizations that responded, all believe that for the most part they are working with a clear vision and mission, even if they could not articulate what these are beyond greater inclusion of people with IDD in the community through community activities and volunteerism. In other words, while the visions and missions of the groups are clear, the ability of many group members to clearly articulate their vision and mission requires significant effort.

The leaders of these organizations generally believe that the membership of their organization clearly understands their purpose for existing as a self-advocacy organization.

### **Responsive and Active Membership**

Across the board, respondent organizations felt their membership is steady and active. Any barriers identified that might impede a member's regularity of participation are seen as external to the management of the organization and are equally spread among such reasons as work or school schedules, transportation, or health. For the most part, though, organizations have a very small group of regularly attending members participating in activities on a regular basis. This type of membership base, though, does not necessarily lead to growth in new membership.

### **Size of Organization**

Of the respondents, the number of active members was quite a diverse range. Two of the groups in smaller, rural communities have an average of five members participating on a regular monthly basis. More than 20 members participate in one self-advocacy organization's activities on a regular basis in a larger community area.

Yet another even larger organization in a major metro area reported gathering between 30 and 50 members monthly. This group benefits from a diverse array of transportation options, some independent drivers, carpooling, support staff providing transportation, county-provided para-transit, and participants that live within walking or a wheelchair's rolling distance of the accessible meeting site.

### **Desired Involvement with Other Self-Advocacy Groups**

A majority of respondents, while few, expressed interest in connecting with other self-advocacy groups across the state, while a small number were unsure or neutral about this. The neutral or uncertain response stems mostly from a concern that each community's organization retain its own identity, a need to

focus on solutions to the group's unique community concerns, and not wanting to dilute their local sense of camaraderie.

Respondents do acknowledge, however, that in advocacy a united voice of many is stronger than scattered voices. The mechanism of how to go about uniting groups separated by miles is a significant concern in a state with a very wide geography and where service types and focus, as well as transportation options/delivery are dramatically different.

Groups wonder what supports would be needed and potentially available for connecting groups across the state, such as technology, transportation, teleconferences, etc.

It is also acknowledged that **it is important that everyone understands broad self-advocacy issues well enough, with easy-to-follow and understand talking points, to enable them to speak up and advocate together as an organized voice rather than in a scattered way (or overly simplistic or highly individual ways)** that seems to lead to group frustration and leaves public officials further confused about what is important among their constituents with disabilities.

### **Community Involvement of Self-Advocacy Organizations**

All respondents agree that connecting with others is an important part of advocacy and building community. Again, it is a question of how.

A multi-pronged approach will be important in connecting self-advocates to advocacy issue information and forums. Approaches might include, but are not limited to:

- Social media engagement,
- Teleconferences,
- Newsletter articles,
- Op-ed pieces in the newspaper,
- Supporting in-person meetings at a mid-point between where current groups meet or switching between sites as accessibility, transportation and communication technology allow (teleconference ability, Wi-Fi access and high speed internet, etc.),

- Holding advocacy town hall-style meetings,
- Hosting self-advocacy refresher seminars and retreats, visioning, and planning strategy activities.

These diverse approaches must include advocates across a broad geography and wide spectrum of abilities and personalities.

All respondents polled said they believed they were well-connected and engaged with their communities where they live because they have community leaders come to their meetings to serve as presenters. As a result, respondents feel their membership can identify their community leaders and understand their job.

Still, transportation is key to getting out in the community rather than just having community contacts come to meetings. At least one of the three respondent groups has agency funded transport to get the membership out to do community service projects, and members do sometimes carpool with family or direct support professionals to events outside their home community, but more consistent accessible transportation is needed across the board.

### **Working with Policymakers**

All respondents strongly affirm that working with their local, county, and statewide policymakers is important in advocacy. Despite the above statement, virtually all expressed the need to better know who their local leaders are, and/or who to ask for support if they want to start an advocacy conversation or activity in their community.

Finding or compiling a current ‘primer,’ or easy-to-follow guide, for contacting officials would be helpful if it also included local/regionally-specific contact information, as well as models of letters and “scripts” that could be used to practice conducting a meeting with one or more officials. It also appears that it would be of benefit to provide information on how to converse on calls to local officials – again in self-advocate friendly terminology that they could use as a reference as needed. Of course, this will also need to be in multiple user accessible formats.

## **Desire for Outside Assistance**

While the written survey resulted in only one self-advocacy organization directly expressing a need for outside support, further conversation with the each of other groups clarified that they were uncertain how they would utilize this support, how deeply the support would/could be involved in their operations and how they could be assured of an exit strategy once the support has been given. Organizations clearly do not want to lose their local structure or focus as they connect to outside resources.

Eventually, as a result of these conversations the majority of **responding organizations want, and express a need for, outside assistance to help them continue with a self-advocacy, person-first focus, to help them grow their membership, or to stay viable as an organization, despite the lack of survey responses to this effect.**

## **Funding Support**

Two organization respondents receive financial support, and have designated meeting space through local service providers. One self-advocacy organization is attempting to be self-supporting with varying, and limited, results.

One of the respondent organizations desires more funding support so they can address the membership's transportation needs to and from meetings, in and around the community, and across the state to practice their self-advocacy skills and to heighten their voice on the state level.

The group further wants self-advocacy training in general, and specifically training and funding support for publicity and printing materials, membership growth, etc.

Further, individual discussions among self-advocate members led to the realization that virtually all of the responding organizations need some kind of financial support and training on how to develop funding streams to meet their future goals and objectives.

Some funding will need to be directed toward training local self-advocate organization leadership to learn how to better communicate among themselves and with their membership, in addition to helping their membership learn effective meeting participation skills, and how to support each other when there are communication and learning barriers. Finally, they will need training on how to proactively (rather than reactively) communicate with their sponsoring agency if one exists.

However, the single most serious issue among the self-advocacy organizations was transportation. Accessible, affordable and available transportation to and from meetings, to and from activities within the community and across the region and state, including conferences, training, and self-advocacy social events is of deep concern.

Once they know how to communicate effectively and establish group harmony, organizations will want to be more present in their respective communities and across the state to engage in self-advocacy activities.

Self-advocacy organizations want (and need) to clearly understand their funding supports and other resources they can access, as well as have a voice in how their organizational funds are spent. Gathering from responses and deeper discussion, agencies hosting or supporting the self-advocacy organizations typically distribute the funding for the self-advocacy organization to function and, as such, can control the agenda of the local organizations. Further, the self-advocacy organizations don't always know how much money is budgeted for them, or for what purpose. Self-Advocacy organization leaders and members desire more fiscal education and supportive control, rather than their perceived situation of no control or knowledge of their funding streams at all.

### **Quality of Membership Communications**

Responding organizations generally stated that they communicate with their membership at least in terms of reminders of monthly meetings. Two organizations further responded that communicating more frequently, and in different ways that others found more accessible, is always better.

Currently, respondents communicate mostly by phone, but some do use email, and most engage in impromptu conversations as members run into one another in their home community.

All agreed they want to figure out ways to communicate better as a group among the membership, as well as between their organization and other advocacy organizations. As of now, the communication between different self-advocacy organizations is poor to nonexistent. Organizations will need to iron out intra-organizational communication issues.

Organizations would greatly benefit from leadership communications training, how to effectively and safely use and access funding for U.S. postal mail, email, and social media platforms. Only once this learning and practice are solid can branching out to learn how best to communicate between groups take place.

### **Concluding Concerns Among Respondents**

Respondents had several concerns they hope to address – and hope that the Advocacy Ambassador Initiative could assist with. These include:

- transportation
- better defining goals and objectives of the organization
- pinpointing funding resources
- remaining active, timely, and aware of national, state and local issues

Self-advocacy organizations want and need supports, but deeply want to develop and maintain their own identity outside the agencies supporting them. Responding organizations expressed a real desire to define who they are and want to be on their own terms without undue influence from an agency that does not share their goals and aspirations. **Self-advocacy organizations want, and need, a better idea of what their group defining goals and objectives are, beyond the identity of their hosting or supporting service provider.** Finally, they want to improve the drafting of their own agendas.

This is another area where leadership development and group communication needs more strength.

### **Section III: Individual Survey Analysis**

The overall approach to information gathering was built upon a combination of presentations to existing self-advocacy groups (a total of nine), mailings to known advocates across the state, presentations at conferences, and a variety of town-hall style, listening sessions. This effort resulted in the Advocacy Ambassadors ultimately engaging with over 500 self-advocates from the mountains to the Outer Banks, with 300 of these interactions being face-to-face. These included the connections made at conferences such as NC Self-Advocates Conference, Partners in Policy Making, and two presentations at the Carolina Youth Leadership Forum.

#### **Survey Development**

Two separate surveys were used for information gathering, one survey to assess organizational need and a second to understand individual perspectives on advocacy, both of which may be found in the Appendix 4 and 5 respectively (p. 62-75).

The intent of the Advocacy Ambassadors for the individual survey was to assess the thoughts and feelings of individuals who have disabilities related to self-advocacy, and to assist the Advocacy Ambassador Initiative of the N.C. Council on Developmental Disabilities to understand what matters most to self-advocates, and how to support people to obtain the assistance they need to have the lives they deserve through coordinated self-advocacy efforts.

The Advocacy Ambassadors also sought to ascertain a person's level of engagement with a self-advocacy group, and in what ways such engagement enhances individual advocacy skills. The final version included a set of questions pertaining to their understanding of the priorities of the NCCDD funded Stakeholder Engagement Group. Those questions (#14-29) relate to the outcomes of: no waiting lists, integrated employment, inclusive living, asset development, and an accountable system.

#### **Dissemination Process and Challenges**

As referenced in the previous section, **the Advocacy Ambassadors encountered many obstacles, as the vast majority of the remaining groups have become polarized in the absence of unifying issues that they felt they understood.** In some extreme cases the Advocacy Ambassadors were met with an overt unwillingness to collaborate. This has greatly affected both membership and individual self-advocacy.

Although in a small minority of situations the Advocacy Ambassadors were unable to circumvent these hurdles, in several situations relationships and trust were successfully re-tooled on the basis of a deeper understanding of the initiative's mission, purpose, and goals. When collaboration was successful, Advocacy Ambassadors were invited to speak at group functions, such as the 2014 North Carolina Youth Leadership Forum, Partners in Policy Making, and several smaller meetings of self-advocates throughout the state providing invaluable access to additional respondents for both the individual and group surveys.

### **Analysis of Findings**

Addressed below are the key findings drawn from the Advocacy Ambassadors' investigation that consisted of surveying individual self-advocates across the state of North Carolina. The vast majority of respondents to the individual survey came from those advocacy groups to which the Advocacy Ambassadors made presentations. Of the 172,000 people with I/DD in the state, the Advocacy Ambassadors were able to make contact with approximately 500 self-advocates, were able to talk directly with over 300 of them, however only seventy-six of them were willing to respond to the individual survey despite the well-coordinated efforts to disseminate, publicize, and encourage candid responses.

While such a low response rate does not allow for statistically valid comprehensive patterns to be determined, the responses *do* reflect a number of important issues across many people in virtually every area of the state.

These most significant of these issues are:

- **The lack of understanding of pertinent issues**, particularly in relation to system wide advocacy;

- **Unwillingness to share candid opinions and sentiments** in writing, either for fear of information misuse or because of overt influence by family or support personnel in answering questions (i.e. major discrepancies between survey results and anecdotal data from private conversations is evident), and;
- Individuals appear to be more capable of ascertaining their personal contentment or additional support needs rather than those not involved with such groups.

Despite an active effort to assure otherwise, it became readily apparent that the survey questions were not as intellectually accessible (understandable) to more of the self-advocates than had been anticipated from our trial rounds.

Thus, the Advocacy Ambassadors had to spend upwards of 70 hours explaining/translating the questions to over 110 individual participants who agreed to allow us to assist them (see below for further information).

The Advocacy Ambassadors received regular comments and questions regarding certain portions of the survey, and the final results showed that many of the same items questioned or commented upon in discussion were later skipped on the paper survey, implying that there were a number of respondents who were confused by some survey items (issues) but were not willing and/or able to verbalize their lack of understanding (not willing to self-advocate for the assistance they needed).

In an attempt to resolve this issue without rewriting the survey, which would have invalidated previous responses, the Advocacy Ambassadors used a variety of approaches, including leading entire groups through the questions one by one and holding discussions about the question's intent before giving people the opportunity to respond.

The Advocacy Ambassadors also reminded participants regularly that the Advocacy Ambassadors were readily available to answer any and all questions. At times the Advocacy Ambassadors sat with self-advocates to support their processing and understanding of each question of the survey.

**The seeming lack of understanding among self-advocates related to disability system issues points to a natural inclination on the part of respondents to focus on personal needs and their immediate struggles** (see below for further discussion). In fact, for some advocates believe that the fight for their *basic* needs may preclude their ability to collaborate with others under a unified vision of system change, resulting in further polarization in the absence of identified unifying issues that they can embrace.

Another significant factor that affected the quality of information acquired from the surveys was observed in those instances where respondents needed direct assistance to fill out questionnaires. While significant measures were implemented to mitigate any effects from outside assistance, such as promoting the use of the online survey and offering support directly from the Advocacy Ambassadors during survey completion, eliminating all external influences of the responses from support staff and/or family members proved difficult.

Over the course of the Advocacy Ambassador's listening process it became increasingly evident that **the barriers self-advocates faced were openly expressed in private conversations, yet survey responses showed vastly different results**. Of particular interest is the discrepancy between conversations around the ability for one to choose where he/she lives or works and the corresponding responses on the survey.

Though not always obvious to the casual observer, the Advocacy Ambassadors observed potential conflicts of interest between providing candid answers to some survey items and the fear of possible repercussions on an individual's care/support. Support personnel too frequently, though not necessarily intentionally, imposed undue influence on final responses.

Of major significance to the Advocacy Ambassador Initiative is the recognition from survey submissions that relatively few self-advocates exhibit a functional understanding of advocacy issues at the system level.

To address the gap in understanding of overarching advocacy issues, it will be paramount moving forward that a major emphasis be placed on education, both through leadership development of individual self-advocates and technical

assistance to self-advocacy groups in order to identify the key issues pertinent to their constituents and developing working agendas to effect change.

In defining a self-advocate driven agenda, the Advocacy Ambassadors expect to see a greater willingness for honesty and candor to emerge as self-advocates throughout the state begin to recognize and take ownership of a collective voice free from the influence of external priorities.

The survey results provides some insight into how currently engaged self-advocates view their support of others and themselves. This is especially true in relation to efforts to improve community engagement, individuals' living, work, and financial situations, as well as support/service needs. However, based on the answers directed at "*how successful have your advocacy efforts been*", we find it is difficult to ascertain if anyone thought any efforts they may have made on behalf of others were successful or not.

The responses to the questions pertaining to system function and people's perception of it (question #20-23) revealed relatively little. **We know from many discussions with advocates, including self-advocates, at all levels, that there is a belief that the system does not function in the best interest of the families and individuals it is expected to serve.** Unfortunately, the formal responses to the survey questions generally do not reflect those same sentiments.

The same issues again arise:

1. Are the survey answers being distorted by external forces?
2. Are respondents avoiding answering negatively, and, if that is the case, why?
3. Are the individuals in this sample somehow significantly different than the larger population we have spoken with?
4. Is it possible that people we spoke with were giving us verbal answers they thought we wanted to hear but these conversations do not reflect their true opinions?
5. Finally, is it possible that the respondents simply do not understand these questions, even though most seem to understand the questions when we are in conversations with them?

Regardless of the reason, there is at least one advocacy issue that needs to be resolved (and probably several). These range from fear to lack of information to an unwillingness to appear in need of support to giving answers to please others.

For example: Results to the questions #1-13 would indicate that a majority of self-advocates feel confident with regard to personal control over where and how they live, work, and engage in the community, and yet anecdotal feedback from both self-advocates and industry professionals exposes several underlying contradictions. **When pressed, many advocates are actually unaware of their freedom to choose anything of substance.**

Further, **rarely are self-advocates aware of the scope of existing options, rendering them ill-prepared to make informed decisions.** Even in situations where self-advocates are sufficiently educated about existing possibilities, **they often feel resigned to their current situation in the face of what they perceive as overwhelming system barriers.**

Engagement with respondents also uncovered incongruities between observed responses and feedback from conversations specifically around employment opportunities and one's ability to readily engage in the community of their choosing. It was observed that **a lack of education regarding employment options** and the individual right to requisite compensation paralleled the education gap identified in other areas mentioned above. At the same time, additional external influences such as availability of transportation seemed to play a far more significant role in perception of free choice by the respondents.

One aspect that remained consistent between survey results and interview responses, conversations, and other accounts, was the **overwhelming need for increased opportunities for greater social and community engagement.** Within the survey itself, responses to questions pertaining to advocates' social lives and need for community engagement (#7 & #8) were virtually the same. Nearly 75% of respondents either *Strongly Agree* or *Agree* that they would like to know more about ways to be connected to their community and would welcome support in expanding their social lives. Given that the vast majority of the survey respondents are, to one extent or another, already involved with a self-advocacy group or are already identified as "strong self-advocates", it stands to reason that the broader I/DD population has an even greater need in this area.

## Findings and Observations

As survey responses, in general, frequently conflicted strongly with feedback from the meetings, discussions, and verbal interactions with those involved in self-advocacy groups, several conclusions may be distilled:

- Conflicting responses throughout the survey process point to an **overall state of disarray in the N.C. self-advocacy movement** that has operated without a cementing purpose or providing a force for change within the community;
- Continued influence of outside parties (service providers and/or family members or others) **interferes with defining agendas for collaboration as well as preventing a clear picture of the overarching needs of the I/DD community** overall;
- Social isolation and lack of connectedness persists as a barrier, even among the most outspoken advocates across the state;
- **Transportation continues to be a barrier for many** to becoming involved in a group or making changes in their lives for work/education, living arrangements, or expanding social contacts, and **many are effectively resigned to social isolation and minimal employment**;
- Survey results differ substantially from direct conversations about system accountability, service provision, and inclusion in system design, with conversations being far more negative/critical, and;
- **Much more education/training is required to close major gaps in most self-advocates' understanding of personal rights, housing options, employment, finances and asset building.**

## Proposed Response for Enhancing Individual Self-Advocacy

In light of the discrepancies between anecdotal observations (as an example, being told by self-advocates that professionals overtook their efforts) and documented survey results (which indicated they felt supported appropriately and not overwhelmed or overtaken by staff), and as a response to the knowledge gaps around such important issues as self-determination, employment, living situations, and system accountability, the Advocacy Ambassador Initiative team proposes a multi-faceted effort.

This would consist of at least the following approaches:

- Development of intellectually accessible modular “Leadership Development” curriculum and other related educational curriculums to be delivered to existing or “newly forming” self-advocacy groups and across the I/DD population, establishing a common reason for engagement;
- Development of an inter-group communication network founded upon identification of common needs and priorities across the state;
- Technical assistance to support the self-advocates’ ability to communicate preferred life situations, including work and social engagement as well as where they call home, to provider organizations and other stakeholders;
- Development of invested self-advocates for leadership roles in existing and new/developing organizations and;
- Establishment of mechanisms to enable self-advocate led agenda design and infrastructure/support implementation.

The effect of these approaches would lead to lessening educational deficiencies while enhancing self-advocates’ abilities to communicate their desires openly and in a productive manner that fosters collaboration in many different situations.

The detailed recommendations are outlined in Section IV.

## Section IV: Recommendations for a Path Forward

Given the above observations concerning the state of self-advocacy in North Carolina, a multi-dimensional approach to strengthening and fostering collaboration among willing and interested parties is required to ensure that the self-advocacy movement within NC becomes both unified and effective in its mission and objectives.

Initially, a strong emphasis needs to be placed on forging a cohesive infrastructure that combines strengthening and expanding self-advocacy groups, the communication between groups across the state, and the development of self-advocate leaders committed to collaborating.

To this end, our recommendation is that emphasis be placed on three most immediate areas of need:

- **Technical Assistance;**
- **Communication and Technology, and;**
- **Leadership Development**

Additional consideration must also be given to the strategic design and formation of an infrastructure that can support and harmonize the evolution of the state's self-advocacy movement over the coming years by self-advocate leadership.

In addition to these three focus areas targeting the enhancement and rebuilding of a cohesive self-advocacy movement in North Carolina, continuing efforts must **build on an established collaboration with the state through the Department of Health and Human Services and Division of MH/DD/SAS in order to enhance access to materials and information to self-advocate consumers.**

Such collaboration could take the form of one or more contracts to provide the following:

- Evaluating current and newly designed materials for intellectual accessibility and ease of understanding
- Translating materials into consumer-friendly formats
- Obtaining consumer feedback
- Support with distribution of materials to self-advocates

- Providing information sessions and events throughout the state regarding consumer advocacy and other topics pertinent to self-advocates

### **Recommendations for Establishing and Infrastructure**

As noted earlier, our findings reveal a substantial need for Technical Assistance (TA), both among existing groups and among pockets of self-advocates interested in formalizing their activities. Activities within the realm of TA may include, but are not limited to the four areas below:

- Strategic development for existing groups, many of which currently operate without key components crucial for successful self-governance such as: published mission and vision, defined goals, by-laws, an identified leader/leadership, and effective Board dynamics
- Team building and communication skills
- Board development
- Incorporation and affiliation strategies for new groups

Technical Assistance efforts will also coincide with, and strive to reinforce, the other two primary focal areas, Communication and Technology, and Leadership Development. **This approach serves to foster sustainability, capacity development, and collaboration for both individual advocacy groups and the state-wide self-advocacy movement.**

### **Immediate recommendations include the following:**

- Support for unincorporated groups interested in formalization
- Formation of standardized and replicable incorporation processes for emerging groups
- Development of a modular curriculum on self-advocacy organization and Board governance to include visioning and course setting, by-law development, and Board function and operations
- Provide additional strategic development to self-advocacy groups as further needs are identified

A recurring theme throughout the investigation process, from conversations with leaders of organizations and individual advocates, was the barrier of maintaining long-term, meaningful engagement among groups and their membership.

**Often, hidden beneath complaints of insufficient transportation or ineffective uses of technology, is the struggle to engage self-advocates in ways that fosters listening, collaboration, and respect, whether within the organization or between groups of advocates. This has caused further isolation among many self-advocates and groups across the state.**

The second area of emphasis, Communication and Technology, would aim to address this through:

- Assessing the specific communication and technology needs of self-advocacy groups throughout the state, particularly those in which transportation is an identified barrier to the group's operations
- Fostering communication and collaboration among self-advocacy organizations across the state
- Identifying groups with aligned goals and interests
- Creating linkages between those groups to promote mutual support.

**Immediate recommendations include these items:**

- Develop a Communication and Technology needs assessment for existing self-advocacy groups
- Partner with local and state-wide technology resources to address barriers with innovative solutions
- Establish an inter-organizational liaison network to enhance conversation between groups
- Build inter-organizational alliances through joint training on topics of common interests

An essential aspect to assure positive and continued growth of self-advocacy within North Carolina, and a fundamental prerequisite toward making the impact of technical assistance and communication building efforts sustainable, is the identification and development of self-advocates with the potential to become

leaders within a unified movement across the state. These individuals must be recognized for their willingness to work effectively with diverse populations and toward common goals.

As highlighted in other sections, historical leadership by self-advocates has been rife with power struggles, personal agendas, and an overarching unwillingness to collaborate.

To address this, the third key area of emphasis, leadership development, will focus on enhancing the skills of cooperation and leadership for both current as well as up-and-coming self-advocates, through training that is not only self-advocate developed and led, but also holds at its core, the principles of inclusion, team building, and collaboration.

In addition to an identified historic unwillingness to collaborate across groups and individuals alike, our interviews and surveys reveal an extremely limited understanding of pertinent issues relevant to North Carolina self-advocates.

To address this, the approach proposed below for leadership development will also prove essential in educating self-advocates about the following priorities:

- Asset development
- Integrated employment
- Inclusive living
- Person-centered planning
- Self-direction
- Medicaid HCBS changes and options
- System accountability, etc.

Through supporting emerging self-advocate leaders with an understanding of how to integrate and advance these priorities within the self-advocacy movement, the results of these efforts will have positive effects throughout the state.

Immediate recommendations around leadership development include the following:

- Development of training focused on collaborative leadership/coalition building for self-advocate organizations to be replicated as a train-the-trainer model
- Creation of leader identification mechanisms and tools for supporting emerging self-advocate leaders
- Development of leadership/Board recruitment training curriculum for self-advocate organizations
- Development of a personalized leadership development program for emerging and established group leaders
- Ensure integration of principles outlined by the SEG into educational modules to be delivered in parallel with leadership and TA modular training

In addition to the above recommendations, it is crucial that consideration also be given to the most efficient and self-sustainable means of implementation.

## **Appendices**

<b>A. 1 National Picture Relative to N.C.</b>	<b>35</b>
<b>A. 2 Stakeholder Engagement Group Priorities</b>	<b>52</b>
<b>A. 3 Stakeholder Interview Questions</b>	<b>53</b>
<b>A. 4 Individual Survey Questions</b>	<b>54</b>
<b>A. 5 Organizational Survey Questions</b>	<b>62</b>
<b>A. 6 Advocacy Ambassador Regional Map</b>	<b>68</b>
<b>A. 7 Advocacy Ambassador Facebook Page</b>	<b>69</b>
<b>A. 8 Advocacy Ambassador Business Cards</b>	<b>70</b>
<b>A. 9 Advocacy Ambassador Brochure</b>	<b>71</b>
<b>A. 10 Advocacy Ambassador Biographies</b>	<b>73</b>

## National Picture Relative to N.C.



at the University of Delaware

### Best Practices in Self Advocacy Organizations:

In this report we provide a history of the self advocacy movement in the United States, a review of existing literature relevant to the self advocacy movement and the operation of self advocacy organizations and a discussion of research conducted to identify best practices, obstacles and, when known, paths to overcome obstacles to self advocacy organizations' ability to self-direct and achieve self-identified outcomes.

### History of Self Advocacy:

---

*In 1968, self advocacy was first introduced as part of the civil rights movement in Sweden. Early writings by Bengt Nirje addressed the disparities that many people with developmental disabilities experience regarding self-determination, respect and dignity (Shapiro, 1993). Nirje called for action to support people to choose and control how they lived their lives, including "personal activities, education, independence, participation in decision making and information upon which to make decisions and solve problems (Ward, 2005, p. 108)."*

---

In 1968, self advocacy was first introduced as part of the civil rights movement in Sweden. Early writings by Bengt Nirje addressed the disparities that many people with developmental disabilities experience regarding self-determination, respect and dignity (Shapiro, 1993). Nirje called for action to support people to choose and control how they lived their lives, including "personal activities, education, independence, participation in decision making and information upon which to make decisions and solve problems (Ward, 2005, p. 108)."

One of the earliest known self advocacy groups was started in 1868 in Stockholm as a social club for people who were deaf. The "Stockholm Deaf Club" still operates today (World Institute on Disability, 2005). This club's foundation and purpose are significant. It was the first non-medically related organization that offered people with similar disabilities to come together to speak about issues they experienced and participate in social and community activities.

The independent living and disability rights movement gained momentum in the 1960s, influenced by the social and political consciousness of other civil rights movements of the

period (Funk, 1987). Individuals with disabilities began relating their own oppression with that of other disenfranchised groups (Lehr & Taylor, 1986).

Ideologies such as normalization (Wolfensberger, 1969) encouraged self advocacy movements in the 1980s as “the drive for inclusion surfaced, criticizing ‘home-like’ and ‘job-like’ simulated programs (Pennell, 2001, p. 1).” Similarly, person centered thinking and planning models that recognized the right of the person using supports as an individual with unique needs, goals and desires aligned with the principles of self advocacy. These principles were further defined by People First in 1974 as members met to support one another and became active participants in decisions affecting their lives (Longhurst, 1994).

Most self advocacy organizations were born out of dissatisfaction with current policies or practices. Most addressed one or more of these major issues: the need to close institutions, end labeling, create legislation to prevent abuse in public institutions or group homes, address

---

*There is considerable evidence demonstrating that when people with disabilities experience self-determination, including choice and control over their services and access to the communities of their choosing, they have better outcomes. The work of the Council for Quality and Leadership demonstrated that when people move from institutions to community settings there is no trade off in health and wellness, freedom from abuse, or safety.*

---

stereotypes, change the criminal justice system to protect people with disabilities, assure that people with disabilities achieve employment and receive competitive wages, increase membership in local civic groups, and/or achieve inclusion in schools (Bullock, 2010).

The concept of self-determination is based on the shift of power from the system to the individual. The goal of self-determination is to offer people with disabilities opportunities to choose how they live and by what means they will be supported (Pennell, 2001). The overall goal of self-determination, explained by Martin and Marshall, is for people with disabilities to be ‘knowing of their choice, by knowing what they want and how to get it’ (Pennell, 2001). Four major principles on which self-determination focuses are freedom, authority, support and responsibility (Nerney, 2012).

There is considerable evidence demonstrating that when people with disabilities experience self-determination, including choice and control over their services and access to the communities of their choosing, they have better outcomes. The work of the Council for Quality and Leadership demonstrated that when people move from institutions to community settings there is no trade off in health and wellness, freedom from abuse, or safety. Community living results in better quality of life and social capital (Council on Quality and Leadership, 2008).

---

*Historically however, well-accepted principles of self-determination have not translated to the social and economic support of self advocacy groups in the United States. In countries such as the United Kingdom, it is common for self advocacy organizations to receive direct funding from the government (Ramcharan, 2005). In the U.S., however, there is no federal source of on-going funding to self advocacy groups. Funding therefore is often provided sporadically and on a case-by-case basis. In some states, Developmental Disabilities Councils or other organizations will write self advocacy organizations into grants or other funding initiatives to both assure that the voices of self advocates are represented and to support the sustainability of self advocacy organizations.*

---

Beginning in 1996, the Robert Wood Johnson Foundation provided \$5 million dollars to help states change their current systems to those that support self-determination. Additional grants have been provided to organizations and groups such as People First and The Arc of the United States to develop programs and trainings to promote and educate people about self-determination.

Historically however, well-accepted principles of self-determination have not translated to the social and economic support of self advocacy groups in the United States. In countries such as the United Kingdom, it is common for self advocacy organizations to receive direct funding from the government (Ramcharan, 2005). In the U.S., however, there is no federal source of on-going funding to self advocacy groups. Funding therefore is often provided sporadically and on a case-by-case basis. In some states, Developmental Disabilities Councils or other organizations will write self advocacy organizations into grants or other funding initiatives to both assure that the voices of self advocates are represented and to support the sustainability of self advocacy organizations. Adequate, on-going funding for self advocacy efforts has been and remains

---

*According to Wolf (2002) barriers to forming a self advocacy coalition include: turf issues, failure to act, dominance by professionals, poor links to the community, minimal organizational capacity, funding, the failure to provide and create leadership, the costs of working together, and costs outweighing the benefits.*

---

limited due to financial and social barriers (Pennell, 2001; Kardell, 2012).

An additional problem is that there has been a lack of inclusion and recognition of the self advocacy community in broader social institutions and efforts. Due to the marginalization of people with disabilities they have experienced great difficulty being recognized as having a legitimate and equal voice (Nussbaum, 2002). According to Wolf (2002) barriers to forming a self advocacy coalition include: turf issues, failure to act, dominance by professionals, poor links to the community, minimal organizational capacity, funding, the failure to provide and create leadership, the costs of working together, and costs outweighing the benefits.

Additionally, self advocates often identify as a barrier to effective achievement of their organizations' goals that they are not given enough time to execute activities and that they do not have sufficient funding to operate effectively. Often the lack of skill, training or support in the areas of leadership, group management, negotiation and ways to access resources are identified as barriers and limit self advocacy groups' participation or efficacy in policy and

---

*Some research has addressed the relationships between self advocates and advisors. Trust and friendship are highlighted as important in a functional relationship between self advocates and advisors (Tilley, 2011). Advisor/self advocate relationships can fall along a continuum of "person-led" at one end, when the advisor provides support but self advocates are in full control of all decisions*

---

advocacy-related efforts.

There has been little research about the structures and functions of self advocacy organizations or how they function in relationship to a larger organization which provides funding or under which they operate (umbrella organizations). Some research has addressed the relationships between self advocates and advisors. Trust and friendship are highlighted as important in a functional relationship between self advocates and advisors (Tilley, 2011). Advisor/self advocate relationships can fall along a continuum of "person-led" at one end, when the advisor provides support but self advocates are in full control of all decisions and "advisor-dominated" at the other end; when the advisor oversteps his/her role by influencing or dominating to too great a degree. Although there are anecdotal accounts of a wide range of relationships, from person-led to advisor-dominated, actual research is limited and necessary to understand how these relationships affect the function and operation of self advocacy organizations (Kardell, 2012).

Although we know that self-determination is related to better outcomes for people with intellectual and developmental disabilities and that limiting choice and control is detrimental to people's wellbeing, we have not successfully applied this knowledge in all instaN.C.es to the successful function and operation of self advocacy organizations.

## **Research Questions**

To begin to address the gaps in knowledge related to the structural and operational supports and barriers to operating effective self advocacy organizations. Issues that were examined include the manner in which self advocacy groups operate; the relationships between self advocate leaders, advisors and representatives of funding or umbrella organizations; as well as structures within and outside of the self advocacy organization that either promote or hinder successful outcomes. This study focused on the following research questions:

- How do self advocate leaders, advisors and leaders of funding or umbrella organizations see their roles in the management and functioning of self advocacy groups? Specifically:

- What are the differences and similarities between self advocate leaders, advisors and leaders of funding or umbrella organizations as they see their roles?
- How do those differences and/ or similarities affect the functioning of self advocacy organizations?
- What are the operational and structural factors that support or hinder successful self advocacy groups? Specifically:
  - What are the similarities amongst successful self advocacy organizations?
  - What are the common barriers, concerns or challenges that self advocacy organizations face?

## Methodology

### Sample

To gather participants, researchers used purposive and snowball sampling techniques (Patton, 2002). First, an internet search for statewide self-advocacy organizations for people with intellectual and developmental disabilities was conducted using national disabilities-related websites. Emails were sent to contacts for statewide self advocacy organizations as well as contacts for each state’s Developmental Disabilities CouN.C.il with a description of the project and a request for the person being contacted to either participate in an interview or send contact information for people who met the participant criteria. Follow-up phone contact was made with people who did not respond to email requests.

As contact information was gathered, each potential interview participant was sent an email containing a description of the project, a description of the participant role criteria and a request to participate and/ or identify potential interview participants. Potential participants were also sent a consent form explaining the purpose of the project, ensuring their confidentiality and indicating that the person could choose not to participate at any time. Each participant agreed to the consent form by signing and sending it back electronically or by consenting verbally during a recorded conversation.

As potential respondents agreed to participate, researchers clarified the person’s role within the self advocacy organization or umbrella organization to ensure that each participant met the criteria. Criteria were as follows:

- **Self advocate leaders:** Identify as a self advocate and hold a position of leadership (preferably president) within the self advocacy organization.
- **Advisors:** Have a formal role and currently act as an advisor to the self advocacy organization.
- **Umbrella Organization Leader:** Holds a leadership position in the umbrella organization (definition below).
- **Umbrella Organizations:** Organizations under which self advocacy organizations operate. The self advocacy organization may receive funding from the Umbrella

Organization and operates under the auspices of the organization or as a program of the organization.

The final sample of individuals with whom interviews were conducted included fifteen self advocate leaders, eleven advisors and nine leaders from umbrella organizations. The sample included people from twenty-three states: New Jersey, Washington, Nevada, New York, Pennsylvania, Delaware, Texas, Kansas, Massachusetts, Indiana, Maine, Ohio, Alaska, Utah, The District of Columbia, California, Rhode Island, Vermont, Wisconsin, North Dakota, Colorado, Connecticut and Louisiana.

### **Semi Structured Interviews**

Researchers clarified each participant's role in order to accurately categorize responses and analyze the similarities and differences in responses between self advocate leaders, advisors and leaders of umbrella organizations. Each participant was interviewed over the phone or in person by trained interviewers.

Researchers created a semi-structured interview for each type of participant. Semi-structured interviews are useful when there are specific research questions but little is known about the interviewee. This approach allows the interviewee to respond to specific topics yet to answer in ways that are relevant and meaningful to them (Patton, 2002). Semi-structured surveys allow researchers to follow up with and clarify responses to ensure that they are truly capturing people's thoughts and experiences (Patton, 2002).

Each interview contained similar questions to allow researchers to triangulate responses and to assess the similarities and differences among the responses of self advocate leaders, advisors and leaders from umbrella organizations. Questions were worded to be relevant to each type of participant. (Survey questions are attached in Appendix A).

Each interview lasted approximately thirty minutes with the shortest interview lasting fourteen minutes and the longest lasting one hour and forty three minutes; this was an in-person group interview of four self advocate leaders from Delaware. Interviews were recorded and transcribed for analysis, however all identifying information, including name and organization was removed from the report to ensure confidentiality.

### **Analysis**

Responses were analyzed using thematic analysis, a method used to identify, analyze and report patterns within data (Boyatzis, 1998). Thematic analysis is a useful and flexible qualitative method that allows researchers to explore and organize data (Braun & Clarke, 2006). Braun and Clarke (2006) suggest a six-phase process that was used which includes:

- 1) Familiarizing yourself with the data,
- 2) Generating initial codes,

- 3) Searching for themes,
- 4) Reviewing themes,
- 5) Defining and naming themes, and
- 6) Producing the report.

Researchers reviewed the results from each interview and individually coded them for themes. Themes were discussed, recoded and renamed by a group of researchers to increase the reliability of the findings (Braun & Clark, 2006). Once themes were agreed upon, the results were organized by research question to ensure that each topic area was adequately addressed.

## **Results and Findings**

### **How do self advocate leaders, advisors and leaders from umbrella organizations see their roles in the management and functioning of self-advocacy groups?**

Participants described their own roles as well as their perceptions of the roles of the advisors and umbrella organization leaders.

#### **Self Advocate Leaders**

Self Advocate Leaders, by and large, described themselves as the leaders of their self advocacy groups using phrases such as, "I am in charge, I make the decisions." Leading, as described by the self advocates interviewed included tasks and responsibilities related to decision making, determining the group's goals, determining self advocacy initiatives and actions, defining roles among self advocate leaders and determining how the group's funds should be spent.

Self advocate leaders recognized that these were their roles, however many of them also recognized that their actual power and opportunities for decision making depended on the other members of their group, the support received from their advisors and their relationship with their umbrella organizations (where one existed). Many self advocate leaders described conflicts between members within the group and problems stemming from people having different goals or wanting to move in different directions. They indicated that sometimes the advisor was asked to (or did) step in to resolve conflict among members.

Self advocate leaders also identified conflicts between themselves and their advisors or umbrella organizations. They consistently described the role of an advisor as a support person to clarify and guide but not someone who should be making decisions. However, they recognized that sometimes "they (advisors) think they know what's best" and that sometimes the advisor did inappropriately share his/her opinions in a perceived effort to convince members to agree.

Self advocates were sometimes unclear of the role and relationship with their umbrella organization (if they identified one as existing). In some cases they stated that because the umbrella organization provided funding this sometimes led to a potential for conflict of

interest. One self advocate leader indicated that the umbrella organization funded group homes and also funded their self advocacy organization which spoke out in opposition of group homes. A few self advocate leaders described frustration with their umbrella organization because they “tell us what to do so that we can get funding.”

In many cases, self advocate leaders recognized that in order to receive funding from their umbrella organization they had to provide a product or serve in a particular role such as providing training or support to an organization or Developmental Disabilities Council. Many did not feel that they had enough of a say in the product they were expected to produce or the role they were asked to play. For instance, one self advocate told the researcher that the Developmental Disabilities CouN.C.il tells them what kind of training they need and pays them to provide training on that topic. While this person acknowledged that it was understood that funds are limited and only available to meet particular needs, the self advocate leader did not

---

*One person indicated that there is often conflict among group members and that when this occurs the role becomes that of a buffer to address the issue before the group as a whole can move forward.*

---

feel that it aligned with the principles of self-determination and self advocacy to be told what type of training was needed instead of being a part of the process to identify training needs.

## **Advisors**

Advisors consistently described their roles as responsible for providing guidance, support and clarity but not to make decisions. Every advisor indicated that the self advocates were the ultimate leaders and decision makers in the group and that their job was to take a back seat and support the self advocates to be decision makers. Advisors did agree that this was sometimes a struggle and that they had to be very intentional in their roles. Some admitted to “overstepping boundaries every now and again,” due to having more experience, knowing more about the situation and understanding the complexity and the context more clearly. They recognized that although they are passionate about the issues addressed by the self advocacy groups, they are not living the experiences of the self advocates and therefore felt that they sometimes needed to provide an objective voice to the discussion.

Advisors also indicated that their role sometimes became that of the peacemaker, either among self advocates in the group, or between the self advocates and the umbrella organizations. One person indicated that there is often conflict among group members and that when this occurs the role becomes that of a buffer to address the issue before the group as a whole can move forward.

The advisors also recognized the potential conflict of interest between the self advocacy groups and the umbrella organizations. They indicated that they sometimes felt pressure from the umbrella organizations to move the group in a particular direction in order to receive funding and felt conflicted when they felt pressure to influence the self advocacy group in this way. When this happened, a few people said that their role became that of an educator for the self advocacy group and as a liaison between the group and the umbrella organization. As educators they tried to help the self advocates understand the pressures the umbrella organization was under or the conditions of the funding. They attempted to help the self advocacy group understand the need for funding in order to succeed and tried to objectively present all sides and brainstorm possible outcomes with the group.

### **Leaders of Umbrella Organizations**

Leaders of umbrella organizations expressed sometimes conflicting values and described how they negotiate that conflict with the self advocacy organizations. Specifically, they recognized that as funders they have a level of power over the functioning and success of the self advocacy organization and that this power has the potential to be in direct conflict with the ideologies of

---

*Techniques mentioned as being used to establish this collaboration included: consistent communication, collaboration on funding opportunities such as grants and state initiatives, involving the groups and leaders in the planning stages of projects and funding opportunities, and evaluation of their own motives and actions towards self advocate leaders and groups to ensure that their behaviors and funding opportunities are always in alignment with the values of the group and principles of self-determination.*

---

self advocacy and self-determination. They described efforts to work collaboratively with self advocacy organizations and leaders rather than having power over them. Techniques mentioned as being used to establish this collaboration included: consistent communication, collaboration on funding opportunities such as grants and state initiatives, involving the groups and leaders in the planning stages of projects and funding opportunities, and evaluation of their own motives and actions towards self advocate leaders and groups to ensure that their behaviors and funding opportunities are always in alignment with the values of the group and principles of self-determination.

At the same time, the leaders from the umbrella organizations recognized that funds are limited and funding opportunities must meet the needs of a particular group, community, etc. They expressed frustration with the idea of funding solely for the sake of the operation of the self advocacy group if nothing was being produced that was of value to them as funders or their communities. A few umbrella organization representatives described a constant communication process that they have with the leaders of the self advocacy groups; they indicated that they sometimes need to remind the groups that funding is only available for

certain projects and that the sustainability of their group may depend on participating in a project that is not directly aligned with their interests and goals.

No umbrella organization representatives discussed any specific conflicts of interest regarding the values or practices of their umbrella organization and the values and goals of the funded self advocacy group. Because researchers were trying to ensure that participants were able to communicate openly and honestly, they were not asked directly to discuss these potential conflicts. However, it is important to note the differences in responses with regard to potential conflicts of interest between the self advocate leaders and advisors and the leaders from the umbrella organizations.

### **What are the operational and structural factors that support or hinder successful self advocacy groups?**

The self advocate leaders, the advisors and the leaders from the umbrella organizations were all asked to identify the structures and systems that support or hinder the successful functioning of a self advocacy organization. Each group noted that any particular factor can have either a positive or negative effect on the successful functioning of a self advocacy organization. For example, each group identified the relationships among the three groups as the main factor that can either support or hinder the functioning of the self advocacy group. Relationships were described as either based on mutual respect and support or based on what self advocates perceived to be dictating activities and direction or an interest only in activities that met the umbrella organization's needs or that could be funded.

The successful functioning of a self advocacy organization was determined by the working relationships among the self advocates, the advisors and the umbrella organization representatives. Successful factors included relationships that were based upon respect, that honored the principles of self-determination and that made the goals of the self advocacy group a priority.

Interviewees from each group indicated that successful relationships incorporated some type of

---

*Interviewees from each group indicated that successful relationships incorporated some type of professional and/or business model.*

---

professional and/or business model. For instance, leaders from umbrella organizations said that when the self advocacy groups were formally involved in the planning and development of funding opportunities and were responsible for reporting their spending and outcomes to the funders, the level of respect between the parties increased. One umbrella organization leader noted that as work was accomplished to professionalize the relationship between the umbrella organization and the self advocacy group, the self advocacy groups felt and acted noticeably

more professionally in all areas, including in their meetings, their trainings and their presentations to the Developmental Disabilities Council.

Self advocates and their advisors agreed that when the umbrella organization treated them with respect as a legitimate and professional group, which included asking them to participate in the development of funding opportunities, involving them in planning processes instead of telling them what they will or will not fund, guiding and supporting them to find additional sources of funding, and training them in areas such as leadership, grant writing, public speaking, etc., they were more successful and able to better advocate and grow as a group.

Additionally, each group noted that it was important for each member to know his or her role and consistently act in accordance with that role. When advisors are able to consistently support, provide clarity and guidance without expressing their own opinions or acting in ways that could be interpreted as coercive, the self advocate leaders felt more empowered, were

---

*Ultimately, there was agreement that the successful operation of self advocacy groups depends on a respectful relationship among all parties: the self advocate leaders, the advisors and the representatives of the funding or umbrella organizations. A mutual commitment to the self advocacy organization's right to determine and achieve its own goals was paramount. These findings align well with principles of self-determination, ideals related to person centered practices and supporting people with intellectual and developmental disabilities to have choice and control over every aspect of their lives.*

---

more satisfied with the outcomes their groups achieved, and were better able to lead their groups with confidence. Similarly, when the leaders of the umbrella organizations were able to work with the self advocacy groups to plan initiatives or seek funding opportunities and were able to respect the group's decision to decline an opportunity or to address a conflict of interest between the two organizations, both groups viewed themselves as better able to build a collaborative relationship and be more successful. One leader from an umbrella organization described a collaboration process in which the Developmental Disabilities Council moved away from being the main funder of the self advocacy group and took on a different role, working together with the self advocacy group to advocate on mutually important issues across the state. This person described this new relationship as a collaborator rather than as a funder as ideal because it allowed the self advocacy group to operate more independently and allowed them to advise each other and provide a common voice on statewide issues.

Ultimately, there was agreement that the successful operation of self advocacy groups depends on a respectful relationship among all parties: the self advocate leaders, the advisors and the representatives of the funding or umbrella organizations. A mutual commitment to the self advocacy organization's right to determine and achieve its own goals was paramount. These findings align well with principles of self-determination, ideals related to person centered practices and supporting people with intellectual and developmental disabilities to have choice and control over every aspect of their lives.

---

*A focus on both respectful relationships among representatives of all groups and business-like practices is the combination that has the best chance of assuring that self advocacy organizations enjoy both the autonomy and support needed to achieve their self-determined goals.*

---

It is important to continually evaluate the practices and values of people who are in positions to advise and fund self advocacy organizations to ensure that adherence to these principles is consistently present. It is equally important that efforts are made to include self advocacy groups in all stages of funding development and to provide training and support so self advocate leaders understand the funding requirements under which their umbrella or funding organizations operate. A focus on both respectful relationships among representatives of all groups and business-like practices is the combination that has the best chance of assuring that self advocacy organizations enjoy both the autonomy and support needed to achieve their self-determined goals.

## References

- Boyatzis, R. (1998). *Transforming qualitative information: Thematic analysis and code development*. Newbury Park, CA: Sage Publications, IN.C..
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Researching in Psychology, 3*, 77-101.
- Bullock, D. (2010). *Learner self assessment: An investigation into teacher's beliefs*. Oxford University Press.
- Council on Quality Leadership (2008). Health and safety: We can do better. *Data Quarterly Publication, CouN.C.il on Quality Leadership, 3*.
- Funk, R. (1987). Disability rights: From castle to class in the context of civil rights. In A. Gartner & T. Jo (Eds.), *Image of the disabled, disabling images* (7-30). New York: Praeger.
- Kardell, Y. (2012). Preliminary riot self-advocacy results. *Not Yet Published*, Human Services Research Institute.
- Longhurst, N. (1994). *The self-advocacy movement by persons with developmental disabilities. A demographic study and directory of groups in the United States*. Washington DC: American Association on Mental Retardation
- Nerney, T. (2012). Communicating self-determination: Freedom, authority, support and responsibility. The tools of self determination. *Centers for Self Determination*.
- Nirje, B. (1969). The normalization principle and its human management implications. In R. Kugel & W. Wolfensberger (Eds.), *Changing patterns in residential services for the mentally retarded* (pp. 179-195). Washington, DC: President's Committee on Mental Retardation.
- Nussbaum, M. C. (2006). *Frontiers of justice: Disability, nationality, species membership*. Belknap Press, Harvard University. Cambridge, MA.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (2<sup>nd</sup> ed.). Newbury Park, CA: Sage Publications, IN.C..
- Pennell, R. (2001). Self determination and self advocacy: Shifting the power. *Journal of Disability Policy Studies, 11* (4).
- Ramcharan, P. (2005). Special issue on empowerment and advocacy. *Journal of Intellectual Disabilities, 9*, 283-287.

- Shapiro, J. P. (1994). *No pity: People with disabilities forging a new civil rights movement*. New York, NY: Three Rivers.
- Tilley, E. (2013). Management, leadership, and user control in self-advocacy: An English case study. *Intellectual and Developmental Disabilities, 51*, 470-481.
- Ward, M. (2005). An historical perspective on self determination in special education: Accomplishments and challenges. *Research and Practice for Persons with Severe Disabilities, 30*, 108-112.
- Wolf, T. (2002). *From the ground up! A workbook on coalition building and community development*. Amherst, MA: United Book Press.
- Wolfensberger, W. (1968). The origin and nature of our institutional models. In R.B. Kugel and W. Wolfensberger (Eds.), *Changing patterns in residential services for the mentally retarded* (59-171b). Washington, DC: President's Committee on Mental Retardation.
- Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation, 21*(6), 234-239.
- World Institute on Disability (2004). *Integrating universal design principles in asset building programs*. Berkeley, CA: World Institute on Disability

## APPENDIX A

### INTERVIEW QUESTIONS

#### Questions for Self-Advocate Leaders

1. Can you describe the purpose and structure of \_\_\_\_\_? (name of organization or group)
  - a. *Prompts: why the group started (for what cause), what your goals are, what the group does, how often you meet, who the staff/ volunteers are, who the leaders are, how the organization is structured (who works with/ for who; whether the organization is under the umbrella of another organization and what organization that is)*
2. Can you describe your role as a self-advocate leader in \_\_\_\_\_? (Name of self advocacy organization/ group)
  - a. *Prompts: Description of job, major responsibilities, common/ day to day tasks*
3. Does the group have one or more advisors; people who help the organization to achieve its goals?
4. *(If applicable- question 3 is yes)* Can you tell me about your relationship with your group's advisor? Can you describe any challenges in working with the group's advisors?
  - a. *Prompts: how do you feel that the person is helpful or not? Can you describe the person's leadership role? How do you feel that the advisor takes on more or less of a leadership role than he or she should?*
5. *(If applicable)* Can you tell me about your group's relationship with \_\_\_\_\_? (Name of umbrella/ funding organization).
  - a. *Prompts: What is the best part about \_\_\_\_\_ as an umbrella for your organization? What are the problems or challenges with them being the umbrella organization?*
6. What are your greatest successes as a self-advocacy organization, and what supported you to succeed?
  - a. *Prompt: policies, organizational structures, specific people, relationships with other organizations, etc.*
7. What are the biggest barriers or problems that you think the organization has or needs to address?
8. What are the biggest barriers of problems that you face as a self advocate leader in your organization?

### Questions for Advisors:

1. Can you describe the purpose and structure of \_\_\_\_\_? (Name of organization or group)
  - a. *Prompts: why the group started (for what cause), what the organization's goals are, what the group does, how often you meet staff/ volunteers, organizational leadership structure (who works with/ for who)*
2. Can you describe your role as an advisor to \_\_\_\_\_? (Name of self advocacy organization or group)
  - a. *Prompts: Description of job, major responsibilities, common tasks*
3. Can you tell me about your relationship with the self-advocate leaders in your organization?
4. What challenges do you face as an advisor?
  - a. *Prompts: Can you describe circumstances in which it wasn't clear how to best advise the organization?*
5. *(If applicable)* Can you tell me about your groups' relationship with the \_\_\_\_\_? (Name of umbrella/ funding organization). Can you describe any challenges of which you are aware with the organization being under \_\_\_\_\_'s umbrella?
6. What are the self advocacy group's greatest successes as a self-advocacy organization, and what supported them to succeed?
  - a. *Prompts: policies, organizational structures, specific people, relationships with other organizations, etc.*
7. What are the biggest barriers that you face as an advisor to the organization?

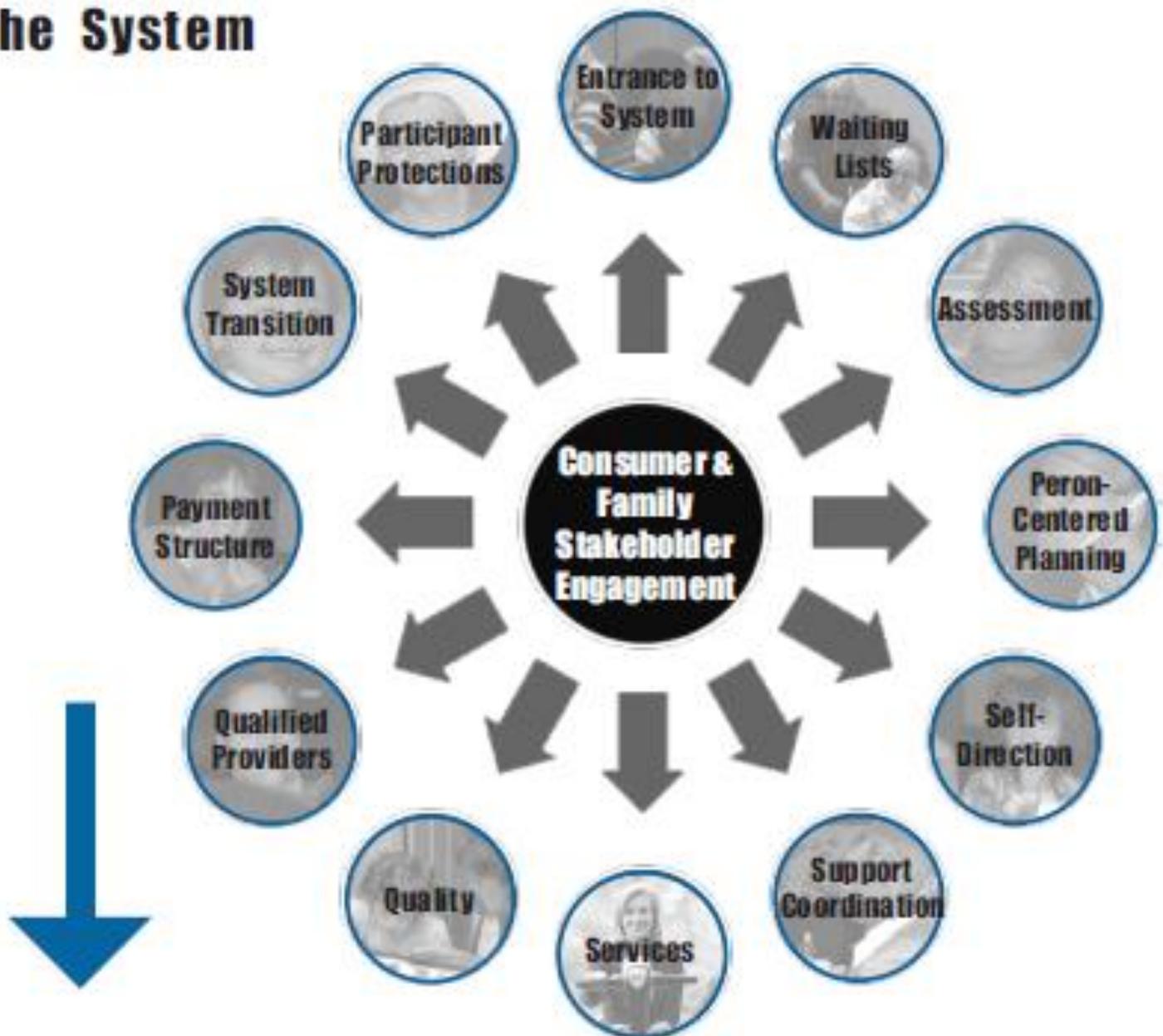
### Questions for Leaders of Umbrella/ Funding Organizations

1. Can you describe your organization's role and relationship with \_\_\_\_\_? (Name of self advocacy organization or group)
  - a. *Prompts: funding structure, supervisors, management and oversight*
2. Can you describe the purpose and structure of \_\_\_\_\_? (name of the self advocacy organization or group)
  - a. *Prompts: why the group started (for what cause), what their goals are, what the group does, how often you meet with self advocacy staff/ volunteers, organizational leadership structure (who works with/ for who)*
3. What are the greatest successes of \_\_\_\_\_? (Name of self advocacy organization) and what supports them to succeed?

- a. *Prompts: policies, organizational structures, specific people, relationships with other organizations, etc.*
4. What are the biggest barriers that your organization faces in relationship to \_\_\_\_\_?  
(name of self advocacy organization or group)

# ● A Consumer & Family Centered Approach for Managed Long Term Services and Supports Implementation

## The System



## The Outcomes

- No Waiting Lists
- Integrated Employment
- Inclusive Living
- Asset Development
- An Accountable System

For more information, contact Co-Chairs of the Stakeholder Engagement Group Michael Mayer, Ph.D., President of National Alliance on Mental Illness (NAMI-NC) at [mikem@nami.org](mailto:mikem@nami.org) or Ron Reeve, Chairman of the North Carolina Council on Developmental Disabilities (NCCDD) at [r77777@carolina.rr.com](mailto:r77777@carolina.rr.com)

## Questions for Representatives Historically Involved with State-Wide Advocacy

1. What has been your experience/involvement with self-advocacy in NC (local, regional, or statewide)?
2. Are you currently active in self-advocacy in NC (local, regional, or statewide)? If yes, how?
3. Can you describe in a sentence or two what you think effective state-wide self-advocacy in NC would look like?
4. Can you briefly describe the current state of self-advocacy in NC from your perspective?
5. On a scale of 1-10, how effective do you think state-wide self-advocacy efforts have been for people with IDD?
6. What do you think are the 5 biggest historic problems associated with state-wide self-advocacy in NC?
7. What would be your top 5 recommendations to correct these problems and/or establish effective state-wide self-advocacy in NC?
8. On a scale of 1-10, how effective do you think state-wide self-advocacy efforts COULD BE for people with ID/DD?
9. What potential resources do you envision being needed to achieve this outcome/score?
10. Any closing thoughts, issues, concerns, suggestions?
11. Can you help us reach organizations or leaders?

## Self-Advocacy in NC – A Personal Survey      PUBLISHED VERSION

This survey is about your thoughts and feelings related to self-advocacy to assist the Advocacy Ambassador Initiative of the NC Council on Developmental Disabilities to understand what matters most to self-advocates and how to support people to obtain the assistance they need to have the lives they deserve. This survey is confidential.

**1. Self-Advocacy Means To Me: (please check all that apply):**

- Helping people learn about my disability
- Speaking for people who cannot speak for themselves
- Talking or writing to people who make laws about issues that concern me
- Speaking up for myself when I am upset about the way I am treated
- Making new friends and working together with them
- Other (please explain)\_\_\_\_\_

**2. I feel free to have hopes and dreams:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**3. I belong to a self-advocacy group that meets my needs and expectations:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**4. I would like to be involved with a self-advocacy group/more self-advocacy groups:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**Self-Advocacy in NC – A Personal Survey      PUBLISHED VERSION**

- 5. I feel I am able to change my living arrangements if I want to:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
- 6. I feel I am able to change my work and/or school arrangements if I want to:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
- 7. I would like to know about more ways to be connected to my community:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
- 8. I would like help in finding ways to expand my social life:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
- 9. I would like to change where I live:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply

- 10. I feel I get (or can change) the services and supports I really need:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
- 11. I want to learn more about my personal rights:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
- 12. I feel my personal rights are respected:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
- 13. I feel empowered to make decisions about my life, including where and when I work, live, love, play, and relax:**
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply

**Self-Advocacy in NC – A Personal Survey**      **PUBLISHED VERSION**

**Please tell us how much you agree with the following statements**

1. I think that everyone who needs services and supports receives them (no waiting list).
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
2. I believe everyone who needs services and supports should receive them without having to be on a waiting list.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
3. I live where I want to live
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
4. I think everyone should work in integrated community employment at competitive wages, with the supports necessary to be successful
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know

## Self-Advocacy in NC – A Personal Survey      PUBLISHED VERSION

5. Everyone should live inclusively in the community, *in housing that is not segregated by disability*, with people of their choice.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
6. Everyone should be able to develop personal and financial assets (like owning a home, having a savings account, and other things that will help prevent you from being totally dependent on others financially).
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
7. The system currently involves consumers and families in the design, development, oversight, and evaluation of services and the system.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
8. The system is currently being continuously held responsible for their decisions, are open and honest about the services and system, and must answer to the public about if people feel they are doing a good job or not.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know

9. The system should be involving consumers and families in the design, development, oversight, and evaluation of services and the system.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
10. The system should be continuously held responsible for their decisions, be open and honest about the services and system, and answer to the public about if people feel they are doing a good job or not.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know

**Have you personally worked on any of the following items?**

1. Have you helped yourself or another person receive services and supports they need?
  - Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know
  
2. Have you helped yourself or another person find integrated community employment at competitive wages?
  - Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know
  
3. Have you helped yourself or another person to live with people of their choice inclusively in the community?
  - Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know

4. Have you helped yourself or another person to develop personal and financial assets?
- Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know
5. Have you helped to make sure the system involves consumers and families in the design, development, oversight, and evaluation of services and the system?
- Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know
6. Have you helped to make sure that the system is being continuously held responsible for their decisions, are open and honest about the services and system, and must answer to the public about if people feel they are doing a good job or not.
- Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know

**Things I wish you had asked me about or other comments....**

---

---

---

---

---

---

---

---

***THANK YOU VERY MUCH FOR YOUR HELP!***

**OPTIONAL (NOT REQUIRED):**

Your Name: \_\_\_\_\_

Please give us information on the best way or ways to reach you:

Phone Number: \_\_\_\_\_

Email: \_\_\_\_\_

Home Address:

(Number) \_\_\_\_\_ (Street) \_\_\_\_\_

(City/Town) \_\_\_\_\_ (Zip Code) \_\_\_\_\_

If you are mailing this back to us – please send it to:

**CRA  
102 West Ruffin Street  
Mebane, NC 27302**

**Organization Name:** \_\_\_\_\_

**Organizational Representative:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Advocacy Ambassador:** \_\_\_\_\_

**1. Our group has a clearly defined vision and mission:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**2. Our group has a dedicated, active membership:**

- Strongly Agree
- Agree
- Neutral/Maybe/Not Sure
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**3. If you have a dedicated and active membership, how many members do you have? \_\_\_\_\_**

**4. Our group has a well-defined leadership structure:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**5. We would like to be involved with other self-advocacy groups:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**6. Our group thinks that connecting with others is an important part of advocacy:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**7. Our group is actively engaged with various members of the community:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**8. Our group thinks that working with lawmakers and policy people is an important aspect of advocacy:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**9. Our group has well defined priorities:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**10. Our group feels confident in our ability to meet possible new members:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**11. Our group accomplished last year's goals:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**12. Our group is stable and strong:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**13. Our group continues to get bigger, stronger, and more effective:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**14. Our group has a clear vision for our future:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**15. Our group could benefit from outside assistance:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**16. Our group has the funding to support our organization:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**17. Our group communicates well with our membership:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**18. Our group would like to communicate better with our membership:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**19. Our biggest concerns are:**

---

---

---

---

---

**20. I wish you had asked me about..../other comments:**

---

---

---

---

---

---

---

---

***THANK YOU VERY MUCH FOR YOUR HELP!***

Please give us information on the best way or ways to reach you:

Phone

Number: \_\_\_\_\_ Email: \_\_\_\_\_

Home Address:

(Number) \_\_\_\_\_ (Street) \_\_\_\_\_

(City/Town) \_\_\_\_\_ (Zip Code) \_\_\_\_\_

If you are sending this back to us – please fax it to 888-542-8555 or mail it to:

CRA  
102 West Ruffin Street  
Mebane, NC 27302



N.C. Advocacy Ambassador Initiative for Self-Advocates

Page Activity Insights Settings Help



**THIS WEEK**

- Page Likes: 0
- Post Reach: 13
- UNREAD: 0
- Notifications: 0
- Messages: 0

PEOPLE 98 likes



Reach a new milestone

Status Photo | Video Offer, Event +

What have you been up to?

N.C. Advocacy Ambassador Initiative for Self-Advocates 15 hours ago

Are you a member of a self-advocacy group somewhere in North Carolina? Sound off! Tell us where you are, the name of your group and where you meet.

Recent

2014 Founded

See Your Ad Here

N.C. Advocacy Ambassador Initiative

The N.C. Advocacy Ambassador Initiative supports self-advocacy groups across North Carolina...

Chat (Off)



**Monica J. Foster**  
Advocacy Ambassador  
Western N.C. Region

Phone:  
**704-490-2063**

E-mail:  
**ambassador.monica13@gmail.com**

Please Participate In Our Survey Here: <http://tiny.cc/c0t2cx>

This project is funded by the N.C. Council on Developmental Disabilities  
and coordinated by Community Resource Alliance



**Jonathan Ellis**  
Advocacy Ambassador  
Eastern N.C. Region

Phone:  
**252-396-1350**

E-mail:  
**ambassador.jonathan@gmail.com**

Please Participate In Our Survey Here: <http://tiny.cc/c0t2cx>

This project is funded by the N.C. Council on Developmental Disabilities  
and coordinated by Community Resource Alliance



**Matt Potter**  
Assistant to  
Advocacy Ambassador  
Project Advisor

Phone:  
**336-409-3096**

E-mail:  
**ambassador.matt13@gmail.com**

Please Participate In Our Survey Here: <http://tiny.cc/c0t2cx>

This project is funded by the N.C. Council on Developmental Disabilities  
and coordinated by Community Resource Alliance



**S. Barton Cutter**  
Advocacy Ambassador  
Central N.C. Region

Phone:  
**919-741-4876**

E-mail:  
**ambassador.barton@gmail.com**

Please Participate In Our Survey Here: <http://tiny.cc/c0t2cx>

This project is funded by the N.C. Council on Developmental Disabilities  
and coordinated by Community Resource Alliance



PLACE  
STAMP  
HERE

MEET YOUR  
ADVOCACY AMBASSADORS  
& ADVOCACY AMBASSADOR  
INITIATIVE  
PROJECT ASSISTANT



Monica J. Foster



Barton Cutler



Jonathan Ellis



Matt Potter

### N.C. Advocacy Ambassador Initiative

W. Ruffin Street  
Mebane, NC 27302

**BUILDING**  
Momentum in  
**SELF-ADVOCACY**  
Across  
North Carolina  
**TOGETHER**

*"Advocacy,  
Advocacy,  
Advocacy  
...and not necessarily  
in that order."*

*~ Ed Roberts*



## What Are We Doing?

For a variety of reasons, self-advocacy efforts in North Carolina have been less than successful over the past several years. At present, there is no recognized state-wide self-advocacy organization.

However, there are a number of self-advocacy groups across the state – with maybe 7 active groups in each of the three regions of the state that may need support to continue to thrive with self-advocates' voices and intentions heard more clearly. Three self-advocates have been chosen as Advocacy Ambassadors to assess and support self-advocacy efforts in their home regions. (Please see the map).

We believe that there is potential for growth within each region - both within each group and through the development of new groups. There is also the potential for collaboration across groups, with self-advocates helping self-advocates, within and across the regions.

Advocacy Ambassadors will meet with all known self-advocacy groups in their region to discuss what self-advocacy means and doesn't mean to each group, and gather information, on where support is most needed so North Carolina's self-advocacy groups can be stronger ever before.

**We Need You!**

## Which Region of North Carolina Do You Live In?



**Contact Your Region's  
Advocacy Ambassador to  
Learn More**

The N.C. Advocacy Ambassadors are working to visit all local self-advocacy groups in the state. The goal of these visits is to find out:

1. Who are the members of the local groups and what do the members want to do regarding self-advocacy?
2. What are the goals of the local groups and what are they currently doing?
3. What help do the local groups need to meet their goals?
4. What are some current positive working relationships and advocacy efforts?
5. Are there possible new and positive working relationships that can help meet these goals?

**Contact Us**  
**N.C. Advocacy  
Ambassador Initiative**  
102 W. Ruffin Street  
Mebane, NC 27302

**Visit us on Facebook:**  
<https://www.facebook.com/NCAdvocacyAmbassadorInitiative>

**Please Participate In Our  
Online Self-Advocacy Survey @**  
<http://tiny.cc/c0t2cx>

## **About the Team Members**

### **S. Barton Cutter**

Barton is a professional leadership coach and mentor who uses his humor and uncompromising wit to empower organizational leaders, youth with disabilities, their families and professionals to discover a clear and powerful vision of their own independence within the communities of their choosing.

He combines his life experience of living with Cerebral Palsy and his professional background of leadership development to bring their vision to life through action steps that are both inspiring and practical.

After receiving his BA from The University of Arizona, Barton spent several years spearheading Youth Leaders in Action, an advocacy and leadership program for junior high and high school age youth with disabilities. Under his direction, Youth Leaders in Action developed a leadership curriculum to empower youth with disabilities to advocate for themselves. Further, he was a driving force behind a statewide conference focused on youth with disabilities and post-secondary education in which he united stakeholders with various interests under a common vision to achieve unified goals.

As the Co-Owner of Cutter's Edge Consulting, Barton has also served as the Communications Director for The North Carolina Council on Developmental Disabilities and Co-Coordinator for the Lifetime Connections Program with First in Families of North Carolina. Throughout 2011 and 2012, he was a monthly columnist for The News & Observer "Our Lives" column. Today, he continues his work with various organizations through speaking and training nationally while offering coaching to private clients.

### **Jonathan Ellis**

Jonathan worked for Easter Seals UCP of North Carolina & Virginia in Wilmington, North Carolina for seven years starting in April 2003. While he was there he served in two roles. One was a liaison between the companies that Easter Seals

worked with through their employment services. He also served as the Liaison between the Social Security Administration and the people who have disabilities, especially ensuring that their wages were reported in a timely fashion to Social Security.

Jonathan has served in many public service roles, including as a N.C. Council on Developmental Disabilities Board member from August 2005 through October 2013. In this role, Jonathan served as Chair of the Community Capacity Building Committee from November 2005 through November 2008. Jonathan also served on the Executive Committee as the Community Capacity Representative. He also served as the Vice Chair of the Council and on the Executive Committee from November 2011 through October 2013.

A well-known public figure and advocate, he has served on numerous other committees and workgroups, currently including the Stakeholders Engagement Group.

Jonathan holds a Bachelor of Arts in Communications with an emphasis in Public Relations from St. Andrews University in 1996, located in Laurinburg, North Carolina.

### **Monica J. Foster**

Monica is a well-known N.C. advocate and vibrant woman who also happens to live as an amputee on wheels, who was born with Spina Bifida and thrives in spite of a diagnosis of Depression.

She lives in Landis, N.C., located in Rowan County, with her husband, Bryan and their rambunctious cats, Annabelle and Poe, and own their wheelchair accessible home. Monica is founder and president of BUTTERFLYWHEEL® Motivation, Advocacy & Consulting, a personal and professional coaching and consulting business that combines her passions for self-determined, independent living, loving relationships, life coaching, energy work, disability access and inclusion. As a professional coach, speaker and consultant, she specializes but is not limited to working with people with disabilities, especially women and female disabled veterans. She is known for working hard to forge alliances among community and business leaders to build an ability conscious society.

Monica, a former two-term Governor's appointee to the N.C. Council on Developmental Disabilities and also a Governor's appointee to the N.C. Statewide Independent Living Council, is a professionally certified life coach, holding endorsements and certifications in life purpose, career, master vision board, with a Bachelor of Arts in English-Writing Studies from Pfeiffer University in 1995. She is also a N.C. Certified Peer Support Specialist through the UNC Behavioral Healthcare Resource Program.

Monica encourages clients and seminar attendees to lead lives 'beyond limits', as she calls living a life impacted by various challenges, especially disabilities, mental health issues, and chronic illness. She uses heart-based coaching activities that nudge clients over, around, and through the obstacles they encounter within themselves and in their communities. She encourages those she works with to shift obstacles into opportunities and challenges into new chances to uncover strengths and new ways to thrive.

Monica is also a nationally sought after speaker and consultant on various disability projects. For example, in just the past few months, Monica presented workshop sessions at the Atlanta Abilities Expo and the 40th Annual National Spina Bifida Association Conference in Anaheim, California. She provides trainings on self-advocacy, providing voluntary physical accessibility and disability sensitivity in the workplace, and inclusion and awareness in the community and schools. With a background in journalism, Monica regularly contributes to disability and self-advocacy focused publications nationwide

Monica is passionate about building self-advocacy opportunities, community collaboration, encouraging competitive employment and small business opportunities. She is also deeply invested in supporting safe, healthy relationships among people with disabilities as she spearheaded the N.C. Relationships Initiative, as funded by the N.C. Council on Developmental Disabilities and administered by Human Services Research Institute. She worked successfully to bring the wants and needs of self-advocates statewide together into one united voice and document called, "A Credo for Meaningful Relationships", which is now distributed nationally.

She currently serves on the Stakeholders Engagement Group, National Spina Bifida Association's Collaborative Care Network Planning Group, and is a founding member and advisory council member of the newly reorganized Spina Bifida Association of the Carolinas (SBANCSC).

### **Matthew Potter**

Matthew currently serves as the Assistant Director to the Advocacy Ambassador Initiative funded by NCCDD. He has been a public speaker and advocate for people with disabilities for his entire life, though it began in earnest during high school. Born with Cerebral Palsy, Matt decided very early on to rise above his challenges and help others to do the same. Matt graduated from Wake Forest University in 2009 with his BA in English.

He is a writer, speaker, Wake Forest sports fanatic, and part-time employee of the Wake Forest University Athletic Department. Matt also recently began work as a test evaluator for Measurement Incorporated in Greensboro. In speaking, Matt aims to make a positive emotional impact on audiences by telling his story and weaving it together with the stories of everyone listening.

Currently, Matt serves as a member of the Board of Directors of both CenterPoint Human Services and The Enrichment Center of Winston-Salem. He is also a former Vice-President of the Winston-Salem Mayor's Council for Persons with Disabilities, Chair of the CenterPoint Human Services Intellectual/Developmental Disabilities Advisory Committee, and a member of the CenterPoint Human Services Consumer and Family Advisory Committee (CFAC).

As an advocate with nearly ubiquitous presence, including his current service on the Stakeholder's Engagement Group and the MH/DD/SAS Medicaid Waiver Review Committee, Matt's dream is to do all in his power to bring together people of all disability service "silos," regardless of who they are representing the issues of intellectual/developmental disabilities, mental health, or substance abuse services, or physical disability, and in the process help create a better future for all through cooperation.