

Leadership for Self-Determination

Self-Determination is	2
The changes we want to make	3
Policy questions	5
Implementation issues.....	6
Social and political change	7
How much of a challenge does self-determination present?	8
How could self-determination be defeated?	12
Signs of failure	12
How failure could happen.....	12
What can we do to move the self-determination agenda forward?.....	15

This report summarizes a retreat for people interested in the North Carolina Self-determination Leadership Network* held at Aqueduct on 18-19 June 1999. The retreat was coordinated by the Center for Development and Learning at the University of North Carolina, Chapel Hill and facilitated by John O'Brien, who prepared this summary from a set of posters and notes made during the retreat and checked for accuracy with participants through verbal summaries. Because the retreat was designed to give participants a chance to explore the implications of self-determination, the group did not make decisions or test for consensus; so not every participant would agree with each point in the summary. This summary does not reflect the position of any group or organization represented by retreat participants.

* For more information about the North Carolina Self-determination Leadership Network, which was formed 12 June 1999 as an alliance of self-advocates and parent advocates working for change in North Carolina's service system, contact either of the group's co-chairs: April Gerard (919.852.1721) and Needham Bryan (919.765.2169). You can also contact Needham Bryan for information about ASANC: The Association of Self Advocates in North Carolina. For information resources on self-advocacy and self-determination contact Rebekah Carswell at the Center for Learning and Development (919.966.5171).

Self-Determination is...

There are at least two ways to speak about self-determination. The first has to do with how people with disabilities live their own lives. Many of the people with disabilities who participated in the retreat described themselves as self-determined and identified one of their self-advocacy goals as teaching other people with disabilities to be self-determining. When used this way, self-determination means things like setting and pursuing goals for yourself, living in your own place free of control by service staff, holding a job, and taking responsibility for making a contribution to your communities. It is about individual people making decisions and taking responsibility for themselves with the encouragement of allies like the other members of a self-advocacy group or a support circle. This encouragement matters because a lot of people with disabilities and their families do not understand their rights and responsibilities as citizens and because, as one person said, "It takes a lot of determination to be self-determined in world where too many people believe the lie that having a disability means not being able to do anything." This way to talk about self-determination for individuals is very important, but it was not the focus of this retreat. This retreat was about changing the way the developmental disabilities system works, which is the second way to talk about self-determination.

This second way to understand self-determination has to do with the way that people with developmental disabilities and their families get public funds and control the expenditure of those funds to purchase the individualized assistance they need to live their lives as productive citizens. It is about changing the service system to put people with disabilities or their families in charge of their own lives by basing services on what people with developmental disabilities or their families decide to purchase from the funds allocated to their individual budget through negotiation with the service system.

The mission statement of the North Carolina Self-Determination Leadership Network, adopted on 12 June 1999 and presented at the beginning of this retreat, identifies the principles for redesigning North Carolina's developmental disabilities service system.

The mission of the North Carolina Self-determination Leadership Network is to create positive change in the current service delivery system. We expect these changes to afford all North Carolinians with developmental disabilities control over their own lives and resources, including

- Freedom to plan one's own life and make choices.

- Authority over one's own life and over resources so that needed and preferred supports can be acquired.
- Access to the support needed (both formal and informal or "non-traditional") to live a life in the community that is rich in community association and contribution.
- Responsible individual action involving participation and contribution in one's community; and
- Fiscally responsible decisions to assure that available funds are accounted for and used efficiently to provide supports that are consistent with these principles.

We will do whatever is necessary to ensure that basic constitutional rights of life, liberty, and the pursuit of happiness become a reality for all in North Carolina.

The North Carolina Self-Determination Leadership network has come into existence in order to bring the work of the North Carolina Managed Care Customer Leadership Initiative into reality. The conclusions of this group, sponsored by the North Carolina Council on Developmental Disabilities, are described in *Choice, change, and community: Charting a new course for customer-driven long-term supports for North Carolinians with Developmental Disabilities* (Final report, October 1997), which participants in the retreat referred to as "the purple book" after the color of its cover. According to one of the creators of the purple book who participated in the retreat, the key to understanding the meaning of self-determination is contained in this paragraph:

We envision a system that assumes that all communities have as members people with developmental disabilities. They are people of equal worth and value to any others in the community. They are people who belong to families and neighborhoods. They are citizens, fellow workers, customers, neighbors, friends, husbands, wives, and lovers. They are not "they" – they are **WE!** (p. 5)

The changes we want to make

Our purpose is to give people the assistance necessary to participate in everyday community life: housing (including home ownership), jobs, education, transportation, recreation, social life, churches and other associations all should be open to people with developmental disabilities. The job of the service system is not to provide separate, special alternatives to community life but to assist people with developmental

disabilities to be productive members of the same communities as everyone else. We believe that self-determination will be a big help in the process of changing services and communities to make everyday life accessible. Informed people with developmental disabilities and family members will, over time, make the kind of choices that will overcome the prejudices and difficulties that now make participation hard for many people. Some of these choices will involve spending available service dollars on the assistance they need in order to participate and contribute.

This will be challenging.^{*} As of 1998 our developmental disabilities system spent about \$600 million on services; about 60% of these dollars were spent in public and private ICF's-MR, facilities that, by design and policy, do not allow for self-determination. Most of the rest of these dollars were expended on services that retreat participants described as low in their responsiveness to control by individuals and wrapped in many layers of regulations and paperwork. And these dollars are under increasing pressure: more than 7,500 people were waiting for services in 1998 and the number of people waiting continues to grow. The result is a system that people with disabilities and family members at the retreat said was well described with the image of "control by a floating head", a head that has lost contact both with the everyday realities of life with a disability and with the heart of service. In this image, the floating head rejects even the simplest and most straightforward proposals if they would threaten to decrease the floating head's power over money and the lives of people with disabilities, people that the floating head can not recognize as whole individuals with personal worth.

An important goal of self-determination is to create negotiations between whole people who represent somewhat different interests. Those representing the system want to maintain the capacity to effectively serve as many people as possible within the available funds. Those representing the person want to assure that each person ends up with adequate, stable funding to allow them to live a decent life. In such negotiations everyone needs to have their heads firmly connected and everyone has to be able to deal with conflicts in a principled and creative way.

In the current system the power base lies with the system. A system oriented to self-determination will turn the power pyramid over; the broadest base of power will be with people with disabilities and their families. Moving self determination forward means coming up with creative answers to both policy questions and to implementation

^{*} Figures from *Choice, change, and community: Charting a new course for customer-driven long-term supports for North Carolinians with Developmental Disabilities* (Final report, October 1997).

questions. It is essential that people with developmental disabilities and their families be actively involved in every step of figuring out the answers to these questions; people and family members should be able to get the help they need to be actively involved.

Policy questions

How do we create fluidity in the use of public money to allow people with developmental disabilities and their families to control the system's expenditures?

- How do we create a unified, flexible funding stream by aggregating different funds and by winning the most flexibility the Medicaid system can allow? How could this unified funding stream include the funds now allocated to institutions and ICF's-MR?
- Where is cash transfer directly to people and families possible and where are vouchers or other mechanisms necessary?
- What principles should govern expenditures? Should any kinds of service be disallowed? How will we deal with conflicts about the use of funds?
- How should people and families account for expenditures?
- How does the state close or greatly reduce money expended on state institutions, ICF's-MR, and large group homes (more than 4 people) thus freeing up money for individualized supports? How far it is possible to go toward closing such facilities depends on...
 - ... the level of political support for facilities, their employees, and supporters
 - ... how we decide to deal with the choice of people or guardians who express a preference for institutionalization
 - ... how we decide to deal with people in facilities who are disconnected from their families and whose choices are very difficult to understand
 - ... how we decide to deal with agencies that refuse to develop local supports for institutionalized people
 - ... whether facilities succeed in defining a new role for themselves

How do we allocate available funds?

- What process will be and appear to be a fair process to give each person with a developmental disability a fair share?
- How will we deal with people waiting for services; will they have a claim on existing funds?

- How will we treat differences in individual or family incomes? Should a person from a family with considerable financial resources get the same amount as a person with similar needs whose family has less money available?
- How will we deal with conflicts about the amounts of money allocated to a person or family?

How do we move closer to sufficient, stable funding? At least four factors influence what amount of money will be sufficient to meet the need:

- The number of eligible people. A number of people, including participants in the retreat, have family members with clear needs for support who are currently not eligible for services. If more people are eligible, the necessary amount of money increases.
- The extent to which people use self-determination to shift to more effective, less costly services.
- The extent to which people and families are able to substitute natural, unpaid assistance for paid assistance, or to substitute other funding sources (for example their own earnings or housing benefits) for DD system funds.
- The wages and benefits paid to direct service workers. It may be that higher pay would result in better quality assistants who are willing to work with people for longer periods of time; this in turn might reduce some people's needs for paid assistance.

What safeguards will we put in place?

- What liability will people and families assume when they purchase their own services? Will this be different if they hire and supervise their own assistants?
- How will we deal with conflicts between people with disabilities and their guardians about which supports to purchase and which opportunities to pursue?
- What will happen if service providers refuse to assist a person because they have an insufficient budget or because they are difficult or unpleasant to support? Who, in anyone, will hold responsibility for being the provider of last resort?

Implementation issues

Each locality will need...

- Ways for people and families to get accurate information about what is possible and about local resources. Some people will be able to get useful information from internet web pages; others will need direct contact with a knowledgeable person. Some people will be able to act on the information they get, others will need a person to help them

open doors and make connections. Some form of switchboard or resource center that puts people with disabilities and family members who know what's possible and available in contact with those who need to know will be helpful.

- People who can help in the formation and facilitation of support circles.
- People who are competent to act as brokers for those who choose to use them. Brokers could be people with developmental disabilities or family members or professionals; what matters is competence, not credentials. However brokers will need access to training and support.
- An effective way to make payments to or on behalf of people and families.

Other resources, which might be developed on a regional or state level include:

- Training in self-advocacy organizing.
- Training for brokers and resource center workers.
- Credit unions to preserve and increase people's wealth.

The pilot projects and the way the state DD system supports them should provide reasonable answers to all these questions. Some questions, such as those that must be answered to establish a unified, flexible funding stream, will have only one answer because they must be answered at the state level. Other questions, such as the design of the allocation process, could have as many different answers as there are pilots. A variety of ways to meet the goal of putting people with developmental disabilities or their families in charge of individual budgets will promote the kind of learning necessary to make self-determination work.

Social and political change

Achieving stable, sufficient public funding; closing institutions and other facilities; and establishing expanded, "no label required" eligibility will require social and political change. That change will come as strong coalitions form between people with developmental disabilities and family members. These coalitions need to be founded on a deep understanding that the constitution is for all people, not just the part of the people without disabilities.

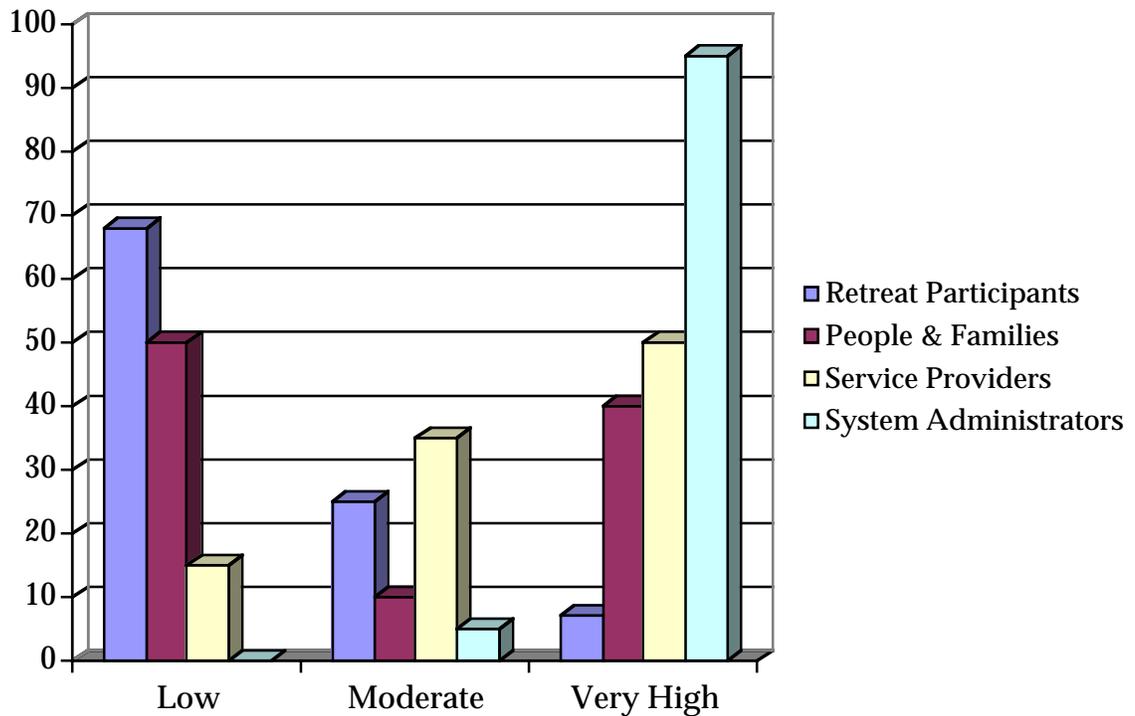
Coalitions will grow as more people with disabilities and more family members get education about their rights and responsibilities and about what is possible through self-determination.

Self-determination is too important for people with disabilities and their families to leave it to system administrators and legislators.

How much of a challenge does self-determination present?

The graph below summarizes retreat participant's perceptions of the degree of challenge the move to self determination will pose for different groups involved with the DD service system. Participants estimated difficulty for each group on a five point scale ranging from " Low challenge: not very different from what we do now" through "Moderate challenge: mostly a change in the way money is allocated and individual planning is done" to "Very high challenge: a fundamental shift in power relationships, beliefs, and ways of working." From their point of view, the change will be most challenging for system administrators, such as Area Program managers and bard members and state managers. About half of retreat participants see a similar level of challenge for service providers and professionals and about 40% of retreat participants see the needed change as very challenging to people with disabilities and their families. Retreat participants see themselves as an exception: almost 70% said that the challenge self-determination presented to them was "very low."

It seems that active support will be necessary from each group: it is hard to imagine success that leaves out any group. This suggests that those who want self-determination will probably need to find effective ways to engage the concerns of those members of each group whose understanding of the world and patterns of work will be most disrupted by the change.



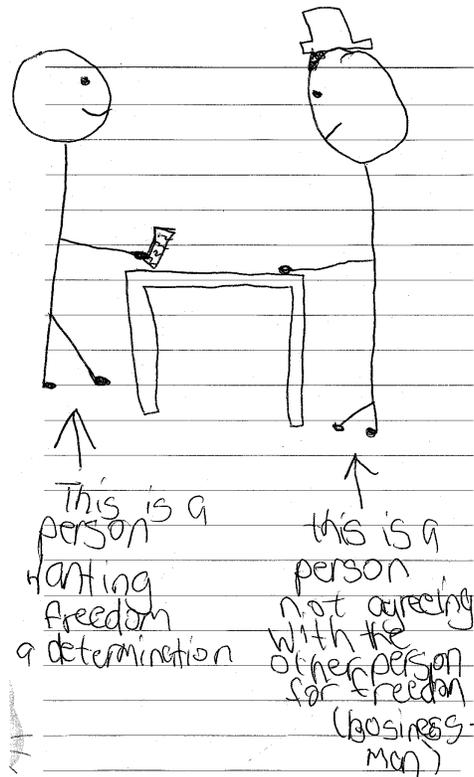
In order to explore the possible concerns of different groups, retreat participants tried to adopt the point of view of the members of each group who would experience the most challenge in changing to self-determination and to empathetically describe what these people might see as potential losses from the change and what they might see as potential gains.

Understandably, this exercise proved challenging. It is easier to attribute negative motives to those, like administrators, who may oppose what we want and have power to block our efforts. Direct conversation with people in each group will allow a check on the negative perceptions reflected in some of the comments below. These conversations have to embody the basic belief: “There is no they: they is WE!” This means monitoring and controlling our own tendency to blame people who threaten what we want..

	Possible losses	Possible Gains
Service providers & professionals	<ul style="list-style-type: none"> - Loss of control & predictability - Fear of job loss if clients can fire you - People/ families will be unfair or poor employers, will buy cheapest vs. best - Staff will lose benefits; get paid less - Loss of investment in buildings - Contribution & role devalued - More overhead costs to manage complexities of individual budgeting means less money for assistance - Belief that we do know what is best for people, or at least that we know better - Concern that people who are difficult or unprofitable to serve will be left out - Loss of professional opportunities, skills, back-up - Agency cash flow will not sustain loss of people 	<ul style="list-style-type: none"> + Greater satisfaction from better meeting people's important needs + Better relationships with people & families because more equal + More opportunities for creativity + Greater connectedness to community + Being part of important gains in people's lives and changes in their communities + People/families may choose to pay more for good services + Good providers will thrive, poor ones will go out of business + De-professionalized system will offer more opportunities for people without formal education
Service administrators	<ul style="list-style-type: none"> - People will choose lower quality or more expensive services for themselves than professionals and administrators would choose for them - Uncertainty about who is accountable, liable for poor outcomes arising from people or family choices - Public support for services may erode - Loss of system they have invested a lot in building - More complex to understand many individual programs than to monitor a few programs - Increased cost of managing a more complex system - More complaints, appeals, lawsuits over amounts allocated to individuals - Concern that people without strong advocates will lose out 	<ul style="list-style-type: none"> + Chance to break provider monopolies + Greater flexibility with money + Not having to have all the answers + Less heart disease + Die with a clear(er) conscience + Deal less with paper/ regs & more with people's real issues + Decreased liability as accountability for quality shifts to people/families + Doing the right thing; working at the state-of-art + No longer the enemy/ scapegoat for failures

<p>People with developmental disabilities and families</p>	<ul style="list-style-type: none"> - Loss of familiar relationships, places, routines - Fear that people will be abandoned or get much less service or incompetent service - Loss of safety net - Families may be expected to do much more for people - People may be exposed to much more risk if they are in control of their supports - Disruption of "need based" or dependant relationships - Increased public visibility of person with a disability might threaten family - More people to deal with; more administrative work to do - No guarantee that you will be able to buy what you want 	<ul style="list-style-type: none"> + Freedom, responsibility, dignity, respect + When you talk, people listen + You get a life + More choice and control over your own life; more responsibility + More flexible & individualized assistance + More risk allows development; more possibilities of reward + A chance to be part of community not just a client in a "therapy" setting + Become the recognized experts + Better access to information, training + More chances to participate in community
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The youngest retreat participant provides another portrait of the difficulty in implementing self determination:



She is concerned that self-determination might not gain the support of people who see services mostly in money or business terms. They may think they are too busy to make room for self determination. She asks, “What happens if I can’t get the money to do what I need to do? What happens to me if we go to court about it and we lose?”

How could self-determination be defeated?

It’s easy for a big change in a complex system to get derailed. Many groups have to let go of things that matter to them; many people’s fears will be stoked by the change. By thinking about how efforts to implement self-determination could fail, retreat participants identified important things to pay attention to.

Signs of failure

Looking back in the year 2002 we see that...

- People are still forming committees, working groups, and task forces. Despite all the talking people with developmental disabilities and their families still do not have direct control over service money. The professionals are the only ones left in the process.
- There is a CAP-SD (self-determination) waiver that allows small amounts of money for limited purchases on behalf of people and families who have been professionally assessed as “able to benefit from self-determination”.
- Pilot sites have become just one more demonstration of a good idea for a few people. Other areas have not adopted self-determination and it even fades in the pilot areas when the project money and attention goes away.
- Any changes in Medicaid waivers affect only a very limited number of people. Most money still goes to ICF’s-MR and institutions. Most of the rest still goes to CAP.

How failure could happen

Fragmentation. Early leaders “own” self determination; though they talk about involving others, they don’t really reach out and they don’t really open-up room for others to make the issue their own and to exercise leadership. A scramble for status and power inside the small group of people who want to own self-determination drives more and more people away.

People fight with each other and cut themselves off from each other because of fairly small differences over what self-determination is. Several different self-determination advocacy groups appear and fight with one another about who has the “real thing.” There isn’t much energy left to deal with the real opposition.

There is a split among family advocates. Some parents of adults are offended and threatened by what they see as an aggressive attitude by self-advocates who publicly reject their families. Many parents decide that self-determination will hurt people with severe and profound disabilities and give more power and resources to developmental disabled people with mild or no cognitive disabilities. Others decide that self-determination will take money away from people already in services and give it to people waiting for services and to people who are not presently eligible. Parents of older adults feel like the parents of younger children are trying to take over a system that younger parents paid no dues to build in order to knock it down. Some parents decide that self-advocacy leaders are the tools of liberal professionals who do not respect family values.

Self-determination is seen as “de-professionalization”. Professionals are insulted and hurt by what they experience as a disrespect for their contribution. They decide that the DD system doesn’t want them and move into other fields. Parents and people who highly value professional services decide that self-determination means giving up the therapies they want and they oppose self-determination.

Advocates for older people and other disability groups see self-determination as a ploy to get even more resources for a group that already gets more than their fair share. Failure to reach out and find a way to make alliances with them results in isolation of the issue.

Those responsible for the Thomas S. class keep class members to themselves. Self-determination has to be something special for them.

Troubles weaken leaders. Working for self-determination turns into one more problem for advocates whose lives are already difficult; they feel even more overwhelmed because self-determination advocates can’t seem to figure out how to support and help one another out, especially when the going gets rough. The stress of trying to make a big change with few allies and lots of conflict among supporters takes its toll. Some people drink more than is good for them, others neglect their own families or jobs, others burn themselves out with overwork, others get cynical and bitter.

Deinstitutionalization. Self-determination gets very closely identified with closing institutions. Under threat, institution supporters mobilize all the political influence they can muster and oppose self-determination as well as deinstitutionalization. The uproar and confusion ties the system up and there isn’t much energy left to deal with self-determination.

Families that support institutionalization argue that self-determination equals the right to keep the status quo. They define efforts to reduce the size of institutions as dictating to them and other families what the “correct” choices must be.

Or: The system does moves big numbers of people from state institutions. This takes priority over making the changes necessary to implement self-determination. ICF’s-MR grow significantly in money and power because they provide the alternative to state institutions for so many people. Big group homes and day programs don’t get smaller or close because of the need to “backfill” them with people from the institution. Moving fast results in poor supports for some people whose problems in area services discredit the DD system in the eyes of legislators, who decide that there is no way that such an incompetent system can handle the problems self-determination would cause. Dealing with a growing number of deficiencies makes the people who administer Medicaid unwilling to support more flexibility in the individualized use of Medicaid funds, “If they can’t run what they already have, how can they handle a whole new kind of risks.”

Managed care. Reorganizing –or considering and opposing reorganizing– the whole mental health, substance abuse, and developmental disabilities system to implement managed care leaves little energy for thoughtful development of self-determination. Advocates for self-determination fail to convince advocates for managed care that self-determination will provide sufficient cost controls. Decision makers conclude that self-determination is just a clever way for the DD system to protect its own interests. The compromises that result from negotiation of these differences threaten the sufficiency of individual budgets and self-determination becomes the mechanism through which many people and families get a lot less money.

Managed care attracts a number of big for profit providers who drive the price of supports down in order to build up their market share before raising prices after putting competitors out of business.

Media. Bad things happen to a few people participating in self-determination and it makes page one. Some people make poor judgements about how to use their funds (e.g. a staff person encourages a group of people to pool their money and take an expensive trip to Hawaii with him) and it makes page one. The media, who haven’t had any other information about self-determination, blame self-determination for these abuses or excesses and opponents pile on. In the political blame hunt that follows, supporters of self-determination loose their credibility and maybe even their jobs.

Money troubles. There is simply not enough money to fund the shift to self-determination. Too few people waiting for service can benefit, so their advocates find little to support in self-determination. Operators of existing high cost services violently object to attempts to cut costs as taking something away from the people they serve.

Regulatory reforms don't happen in a way that reduce costs very much, and any money that does get saved is eaten up by the costs of converting organizational systems to operate self-determination.

Poor politics. Advocates for self-determination seem to legislators to be self-righteous and naïve. They seem to like acting militant and demanding better than doing what it takes to develop legislative interest in the issue. They talk big without any facts to back up their arguments. Legislators point out that the constitution doesn't guarantee anybody the pursuit of happiness at public expense. The advocates for self-determination fragment over tactics: those who try to negotiate get labeled as "selling out."

Or. Advocates for self determination act shy about the legislature and other officials. Self-advocates and family advocates leave lobbying to the pros. They don't take responsibility for planning and carrying out a systematic campaign, it's almost like they would rather complain that legislators and members of the executive (like the people in charge of DMA) don't understand them than have the discussions that will involve and educate them. This means that the groups who have already cultivated close relationships with decision makers will continue to exercise most influence.

Because the issue never made any connections to community members outside the DD world, legislators see self-determination as just one more tactic by a special interest group inside a special interest group. People across the state don't personalize the issue with legislators.

Over-promising. Advocates claim that self-determination will be cheaper and result in significant growth in people's independence and satisfaction. Because it doesn't always work out that way, many people decide that the facts (or the research) don't support self-determination.

What can we do to move the self-determination agenda forward?

Strengthen the base of support for self-determination by strengthening and expanding the network.

- Make strong links between self-advocacy groups and parent advocacy groups. Be sure that they UNDERSTAND how changing the way the DD system allocates and uses

money fits with their interest in leading better lives. Encourage people involved in training with ACT to apply the SPIRAL model to the issues of moving the DD system to self-determination. Be sure that there are specific ways that interested people and groups can work to make the change so that people who understand the importance of self-determination can get to work right away,

- Explore alliances with other disability groups outside developmental disabilities and with groups advocating for older people. How does changing the DD system connect to their agendas?
- Make personal contact with the people in the “inner-circle” of political power around the DD services system to explore what it would take to gain their support for self-determination.

Support the self-determination pilot projects with very high expectations for real change in who controls the money rather than just talk, and prepare the ground for self-determination to expand across the state.

- Work for a Medicaid waiver that will support self-determination and flexible use of funds to meet individual needs. Lobby the state’s members of Congress for help with HCFA.
- The whole system spends a great deal of time and energy conforming to unnecessary regulations and complying with redundant ways to assess services. Throwing out unnecessary regulations and settling on a single way to assess and improve service quality would free a lot of system administrators’ and service providers’ energy for work on self-determination.
- Lay the foundations for a single unified funding stream for all developmental disabilities services.
- Personalize the successes and issues around self-determination to legislators. Legislators from the pilot areas should become political champions for extending self-determination throughout the system.
- Involve the media from the very beginning of the self-determination pilots. Media people should know what self-determination means for people with developmental disabilities and their families from the very beginning. They should report on the issues that make self-determination necessary as well as on its successes for people. This won’t keep any problems that do happen out of the media, but it will provide an important background so that self-determination doesn’t get sunk by a single incident.

- Don't let the pilots carry the whole load. Any area program can implement self-determination whether they are a pilot or not.
- Involve individuals and families with no previous relationship to people with disabilities directly in assisting people with developmental disabilities to make the best of self-determination. This is especially important for people with developmental disabilities who have lost contact with their families and have few or no relationships outside the service system. Make self-determination everybody's business.
- Make information about self-determination widely available both through the internet and through person to person contacts. Set up a speaker's bureau of teams of people with developmental disabilities and family members who will teach people about what self-determination is and how to make it real in the DD service system using the HSRI curriculum as a starting point. Identify county contact people across the state so that interested people can connect person-to-person. Be sure that self-advocates and family advocates keep feeling the challenge to understand that self-determination is for all people with developmental disabilities, not just people with a particular level of ability.
- Keep getting together all the people interested in how to make self-determination work to review what is happening, share successes, and examine barriers and dilemmas. Make the learning from this work widely available.

Invest in activities that will have positive long term effects on the ways people with developmental disabilities can use the choices they gain from self-determination.

- Keep organizing adults with developmental disabilities to increase their opportunities and abilities to make responsible choices and contributions as citizens.
- Start organizing children and young people with disabilities, starting with teaching elementary school students and their families in personal self-determination.
- Make an understanding of self-determination an expected part of transition planning for young people with developmental disabilities.
- Change expectations among other citizens by making self-determination and other disability issues part of the general curriculum in schools at every level, for example in parenting classes.
- Encourage people with developmental disabilities to be part of community boards and action groups that influence important opportunities outside the DD service system, for example a local transportation board.

- Encourage people with developmental disabilities to be politically active. If a campaign worker doesn't have a car, getting a ride from another politically active person (maybe even the candidate) offers a great opportunity to educate people on disability issues.
- Encourage people with developmental disabilities to run for office. This is a great way to make citizens familiar with what people with developmental disabilities can contribute even if the candidate doesn't win.
- Keep working for stable funding for DD services which is sufficient to meet the needs of all North Carolinians with developmental disabilities.