
16 Partners in Policy Making Far More than the Object of Policy ...

Tara Barenok and Colleen Wieck

For those of us who remember it, analysing sentences for grammar class was a laborious task. Most times it went like this: pick out the subject, pick out the verb, see if there is an object. Basically you tried to answer the question: 'Who did what to whom?' Sometimes, analysing public policy can be the same way. People with disabilities and their families all too often are the objects of policies instead of helping to set the rules (either legislated or agency-set) that govern their lives. In 1987, an idea was developed in Minnesota to rearrange the parts of the policy sentence. 'Partners in Policymaking' was designed to provide leadership training to parents of young children with disabilities and adults with disabilities. The program has been replicated in over forty United States and in the United Kingdom. The lessons and values of the program have applications across social policy areas and across oceans.

What is Partners in Policymaking?

Partners in Policymaking is a leadership training program which teaches what works in disability services and supports to the people who have the most experience with what is needed in systems change - individuals with disabilities and parents of young children with disabilities. This hard won expertise combined with the policy tools and strategies that the program presents are the best formula for ensuring a vision for the future. This vision focuses on the independence, integration, inclusion and productivity of people with disabilities in their communities. The program is typically run or funded by a state developmental disabilities council or funded by a private foundation.

The program has 128 hours of instruction provided over eight weekends, with one weekend session each month. This time commitment ensures that Partners 'learn how to learn.' 'What works' (otherwise known as: 'best practices') are a moving target. Continuous improvement of processes means that a person simply cannot any longer learn what works and keep applying the same model indefinitely. The topics of the Partners programs are general enough so that continuous learning is the aim of the session, not acquiring any specific set of knowledge. The time period between each session ensures that Partners get a chance to practise their skills through homework assignments and incremental work towards the completion of a major public policy project.

Why did it come about?

In 1987, Colleen Wieck, Executive Director of the Minnesota Governor's Council on Developmental Disabilities and Ed Skarnulis, Director of the Developmental Disabilities division at the Minnesota Department of Human Services, were struck by the leadership vacuum among young parents and people with disabilities (self-advocates). The average age of members of national associations on developmental disabilities were creeping steadily upwards. Few if any self-advocates were involved in setting direction for these organisations. The need for parents and self-advocates to learn how to make effective systems change was evident. The gains of the disability movement were at stake.

What are the Quality Principles of the Program?

In order to ensure that the program meets its ultimate outcomes (independence, inclusion, integration and productivity for all Partners and their family members), the design of the program built in quality principles that served this end:

Experiential learning

Partners learn by doing. They prepare and deliver testimony to public officials or their representatives. They practise catching public officials in the hallway and getting their stand on an issue across in few minutes. Both parents and self-advocates benefit from the experience of the other

group. They use a variety of different learning methods to acquire a very specific set of competencies.

Diversity

Partners groups are diverse in experiences, disability types, geographic location, gender, racial and ethnic backgrounds, income levels and education levels. Partners learn as much from the experiences of others as from the curriculum.

National speakers

Partners obtain training from speakers who provide a national perspective. These speakers are not inhibited by their roles in the state where the program is operating - either they are from outside the state or their job in the state is to make these specific types of changes.

Best practices

Partners learn about what's possible, not about what they already know - the current system of services and supports in their state or area. They break out of the status quo and ask: 'What if...'

Leadership

Partners acquire knowledge not just for knowledge's sake. They take things they learn and take action for social change. They provide leadership for their communities. It's not about getting the most services for themselves and their families: it's about getting what they need and making sure others have the same opportunity.

Length of time

Funders make a commitment to the Partners programs for a full eight weekend sessions of training. Partners receive 128 hours of instruction over the course of a program year.

Sufficient funding

Funders commit themselves to pay for all the program related expenses (meeting space, meals, accommodations, respite and child care, and

travel expenses). This money supports the other quality principles. Without addressing these concerns, Partners can't take the first step towards participating.

Evaluation

Partners and speakers evaluate their experiences with the program. A baseline survey is taken of Partners with six month and long term surveys following graduation. These results are tracked and monitored for long term trends. Changes in the program are implemented based on these assessments.

Not an organisation

Partners is a training program - the real work of graduates is in the community, state and national organisations. The program links them with networks and helps them acquire the competencies needed to succeed. No national database of partners exists. A person can't pay 50 dollars to join. After committing to the program and following through with attendance and hard work, a person is a Partner and goes on to change the world.

What are the Values by which the Program Judges Itself?

A quality Partners in Policymaking program is built on the inherent human rights and responsibilities of people with disabilities. Every aspect of the training program must reflect these values - otherwise the program is not living up to its funder's expectations or the quality principles.

People with disabilities are people first: the disability should come second, if at all. Labelling goes against the point of the program - best practices in disability services. If best practices are always changing, giving someone a static label by which their life is defined will be ineffective at best and highly damaging to the person's ability to define him or herself at worst.

People with disabilities need real friendships, networks and bonds, not just relationships with paid staff. All Partners are entitled to establish the

connections with each other and policymakers that they need to succeed at making systems change.

People with disabilities must be able to enjoy full mobility and accessibility that allows active participation in community life. This includes physical accessibility but goes beyond it. Learning methods and program materials must be modified so that everyone has a fair shot of attaining the skills they need as systems-change advocates.

Continuity in the lives of people with disabilities is highly important. This continuity takes place through families and neighbourhood connections. Partners programs reflect this need. Again, Partners is not an organisation to which people can belong and not belong, based on membership dues or other signs of allegiance. It is a continuous presence in the lives of people who have gone through the program, providing the support and tools people need to achieve their personal and systems-change goals.

Dignity and respect of people with disabilities is critical. How can a person expect to succeed at changing policy and systems for the better if they cannot respect the other people who are changing it and who will benefit from its change? This also means that Partners are encouraged to respect themselves and their experiences in ways that they may not have before.

People with disabilities must be in positions to negotiate to have their wants and needs met. These positions may be informal, like serving as an on-call adviser for a policymaker who respects and needs the opinions of a person with experience on disability issues. These positions increasingly have become more formal, with Partners graduates taking on policymaking roles as elected and appointed officials at local, state, and national levels.

Choice is critical for people with disabilities in all areas of their lives. These choices are no more, no less, the same rights that people without disabilities have.

People with disabilities must be able to live in the homes of their choice with the supports they need. Institutions and other settings with large numbers of people living together without input into their living arrangements are the thing most antithetical to best practice in disability services.

Productivity through employment and/or contributions as members of their communities is not only the right of people with disabilities; it is their responsibility. People with disabilities work and succeed in competitive employment when this responsibility is recognised by employers.

What does the Program's Curriculum Look Like?

The curriculum is experienced over eight weekends, with 128 hours worth of instruction for each class of Partners. National speakers provide the training. Logistical and program arrangements are made by a coordinator. Each weekend has certain competencies which Partners will attain in the course of the weekend and through completion of homework assignments. The program covers two broad sets of topics:

Life area topics

As the name suggests, these topics give Partners details on the best practices in how services and supports are provided. The presenters are people who are the best at what they do in the country. For example, an inclusive education expert exposes the class to what works with children and young adults in classrooms. The other life area topics are assistive technology and positioning, competitive employment, and independent living and a home of your own.

Policy and systems topics

Partners learn how to interact with federal, state, and county elected and appointed officials. They learn how to write a letter, prepare testimony and other critical skills to access policymakers and their staffs. These tools are effective and proven strategies that will build systemic change possibilities. Community organising is a critical skill that Partners learn. Parliamentary procedure is also covered, with emphasis on both learning

how to follow a meeting in which these rules are used and learning how to use the tools for the meetings that Partners will lead themselves.

In both types of topics, Partners learn in interactive ways such as role playing, group activities and small group discussions. They practise giving testimony before actual legislators and their staffs. They discuss issues and concerns directly with state agency employees in a neutral setting. Homework is assigned and Partners report back on their experiences and impressions so that a multiplier occurs - not only do Partners gain their own perspectives on how the system works but also they are exposed to the perspectives of others. Partners get practice at doing what they continue to do after graduation - advocate on behalf of themselves and their families.

How do Programs Ensure that Competencies are Met?

In Partners programs, there is a three pronged approach to ensuring quality improvement. First, long term evaluations are conducted by external evaluators to compare the activity levels of Partners at a baseline before the program, six months after the program and for up to five years after the program. Questionnaires are mailed to Partners. A high return rate has been experienced by programs that have fully implemented this approach. The results are tabulated and analysed for improvements to the program.

Second, the program coordinators evaluate themselves and are evaluated by the funding source. Most programs evaluate quarterly which is more frequent than most grants made by foundations and other funders. This frequency allows programmatic and logistical issues to be corrected quickly and to the greatest effect for participants.

Third, Partners evaluate presenters and the way the training is delivered after each session. The program coordinator takes these suggestions and adjusts the program accordingly before the next session as needed. Comments on presenters are used to determine who will present the topics for the next class.

What Happens to Partners after the Program?

Partners become systems-change advocates. They use the skills and abilities they have developed to influence policies to make the lives of people with disabilities better. A few Partners graduates have served as Kennedy Fellows in the United States Senate. These people provide the Senate committees that address disability issues, with the critical expertise they need from people who know both how the system works and how to make it better. Several Partners graduates have been elected to local and state positions. Many more have been appointed to boards and commissions that directly set the terms of debate for disability policy. Perhaps most profoundly, there are literally thousands of people in the United States and the United Kingdom who share the same expertise and are able to make their own lives and the lives of others better.

Many states provide Partners with funding for continuing education or opportunities to learn new skills as they go through their systems-change activities. These supports are an important refresher for all who take advantage of them. People need these refreshers to continue to be effective.

What Challenges has the Program Faced?

Two main challenges have faced the program since its inception. These challenges are: involving people of diverse cultures in the program and ensuring quality implementation and replication of the program. The Minnesota Council has evolved strategies to deal with each of these issues.

Since 1992, the Council has funded leadership and cultural diversity projects. The first project evolved out of a request from an African American community leader regarding educating parents about their rights given the fact that African Americans are over-represented in special education and the juvenile system but under-served by family support programs. The second project evolved from the Council's recognition of other unserved groups such as Native Americans and others. Each project involves several meetings over six to eight months to provide

parents with information on their children's rights. The baseline surveys from both groups found that few of the parents knew that their child had specific rights to education and other services and supports.

The continuing challenge of these projects is to give these parents enough information so that they can participate in the full Partners program. Each project hopes to not only give people the tools they need to participate or even think about participating in Partners but also to give them some concrete tools they can use immediately.

Ensuring the quality principles of the program has become of increased concern in recent years. The Partners model was carefully crafted over a period of several years. The first replications outside the state of Minnesota ensured that the model would work in a variety of settings and on a range of budgets. However, the continuing challenge of advising close to 50 replications worldwide has revealed two experiences. First, programs have tried to modify the quality principles of the program, sometimes out of an honest desire to improve the program and sometimes out of a need to cut budgetary corners. When this happens they often run up against the problems the quality principle was intended to prevent. For example, some programs have tried to have all in-state speakers present on inclusive education. Unfortunately, the speakers may be limited by the roles they play in the state's education system and cannot present the information the parents need to know to demonstrate the competencies regarding inclusive education. The Partners are frustrated: the speaker is telling them about the system they already know too well instead of best practices. The effort to cut corners actually ends up wasting the program's money and the time of everyone involved.

The technical assistance the Minnesota Council provides to program replications has revealed a second experience. Programs have tried to skimp on the evaluation component. Some programs decided not to track long term outcomes by using an external evaluator. Other programs decided to forgo evaluations of each and every speaker of the weekend, opting instead for getting feedback from Partners only on the main speaker or for taking more informal, on the spot, verbal reviews. In either

case, these programs have faced considerable threats to their funding or in extreme cases discontinuation of the program. And without demonstration of effectiveness, who could blame the funders?

In response to this need, the Minnesota Council provides technical assistance to the programs on an as-needed basis. This includes phone calls, email and faxes in the weeks preceding sessions and the beginnings of classes. Coordinators are referred to each other for onsite visits of programs or invited to visit the Minnesota program. In addition, coordinators receive a handbook, including useful forms and instructions on quality replication of the program. This handbook is revised every two to three years to keep up with quality improvements and to give coordinators the most up to date information on speakers and topics. Coordinators are also invited to seminars and academies every year to two years where face to face technical assistance is given. Reflecting the quality principles, the Minnesota Council is constantly evolving new and better ways of helping programs by remaining responsive to their needs.

Where has Partners been Replicated?

Partners programs are currently operating or being planned in 42 United States and Territories. Three states and territories are considering operating the program in the future. Just four states and the District of Colombia have never operated the program. Three others previously operated the program but do not do so at the time of writing. There are six sites planning or operating in the United Kingdom. A program has been funded by UNICEF to begin in the Philippines.

Note

If you are interested in finding out more about Partners in Policymaking in your state or territory or to get additional information on the program, please contact either of the authors at the address below.

For information on Partners in Policymaking in the UK contact:

Circles Network,
Pamwell House,
160 Pennywell Road,
Upper Easton,
Bristol BS5 0TX

Tara Barenok is now working for the Minneapolis Budget Office having previously been a Management Analyst at the Minnesota Governor's Council on Developmental Disabilities. She has worked on quality issues, planning, and human rights connections for the Minnesota Council. Tara also worked for Minnesota Advocates on Human Rights and the International Human Rights Internship Program.

Colleen Wieck is the Executive Director of the Minnesota Governor's Council on Developmental Disabilities. She has worked as a direct services provider for five years, as a researcher for three years, and in her current position since 1981. In addition, she is a consultant, evaluator, expert witness and public speaker. Colleen has also been an active member of several national organizations such as The Association for Persons with Severe Handicaps, the Association of Retarded Citizens - United States, and the American Association on Mental Retardation, as well as several national committees.

Contact address

Governor's Council on Developmental Disabilities
300 Centennial Office Building
658 Cedar Street
St. Paul
Minnesota 55155
USA