

Introduction

In 1998 Removing the Mask published *More Than Good Intentions*, an analysis of policy and system change necessary for self-determination to take root in Ohio. In the year or so since its publication Removing the Mask has increasingly focused on two of the topics introduced in that report: leadership and funding.

In September, 1999, Removing the Mask sponsored a one-day conference, “Investing in Futures: Making the Money Work.” People from around Ohio and invited national resource people considered how we invest public resources now, and how we could reinvest them in ways that make it possible for people to increase their control and direction of their own lives.

The conference was organized around four discussion strands.

- Moving toward more equitable distribution of resources among those who are eligible for them, including those who are waiting for services
- Shifting dollars from program funding to individual supports
- Using the creativity and flexibility possible within current Medicaid standards
- Strengthening the capacity of individuals and families to understand how the money works and to direct individual budgets

A national perspective on these issues was provided by resource persons Charlie Lakin, from the University of Minnesota; Michael Head, Michigan Self-Determination Project Director; Gary Smith, from the

National Association of State Directors of Developmental Disabilities Services; and a team from Rhode Island, consisting of Lynda Kahn, Director of the Division of Developmental Disabilities Services; Deanne Gagne and Deb Kney, of Advocates in Action, and Doreen McConaghey, of Parents for Alternative Living. Conference participants included self-advocates, parents and representatives of 30 county boards, the Ohio Department of MR/DD, the Ohio Department of Human Services and provider organizations.

This report is based on background materials for the conference and discussions that took place during the conference. Ideas included in the report do not represent consensus positions among those who attended. Breakout groups generated many ideas, many of which are included here.

As *More Than Good Intentions* noted, “Funding is the true expression of public policy. The allocation and use of resources represent the priorities of government and dictates what people expect to achieve with public resources.” The present report considers several questions that shine a light on the priorities current investments represent and ways that funding could better align itself with evolving priorities:

- How are public resources invested now?
- What problems do we face with current investments?
- What possibilities have we seen for reinvestment?
- What is there for us to do to make possibilities realities?

The way the money works

Overall Investments:

- Nationally \$27 billion go into state MR/DD service systems. In Fiscal Year 1997 federal, state and local dollars in Ohio's MR/DD system totaled \$1.9 billion. Compared with other states Ohio is above average in the amount of money going into the MR/DD system.
- Ohio's MR/DD system has been able to use state dollars to bring in more federal money. Success in raising Medicaid funds may have sent the legislature and the public the message that state money is not needed.
- Almost every state has created major growth in its human services system over the last decade, yet this growth is 25% below the level necessary to stay even with waiting lists.
- As noted in *More Than Good Intentions*, "Each funding source used or developed has been typically designated for certain purposes or otherwise restricted in its use."
- People tend to think categorical funds are even more categorical than they are. For example, implementation of the Residential Facility Waiver enabled county boards to raise an increased amount of Medicaid money through CAFS. In most places CAFS was seen as Adult Services program money that should stay there, rather than money that could be used in the area of greatest need.

- Of \$474 million levied at the local level by county boards of MR/DD throughout the state in FY97, \$112 million matched federal money, leaving \$200+ million at the local level not being used to leverage federal money.

Medicaid:

- Ohio has initiated a number of Medicaid programs over the years – ICF/MR, CAFS, waivers – but these programs are not stitched together. People's supports, and their lives, tend to be determined by which of several Medicaid funding mechanisms they use.
- Compared with other states, the number of Ohioans in ICFs/MR is disproportionately high and the number of people using Medicaid waivers is disproportionately low.
- In Ohio programs and services vary from county to county. Offering people different services based on where they live is inconsistent with Medicaid's principles of statewideness and comparability of services. People should not be discriminated against on any factor except whether they qualify as Medicaid-eligible and whether they need what is provided. The statewideness issue has to be resolved to preserve the security of the waiver program.

"Legislators do get the idea that developmental disabilities systems are well funded. It's important to look at new resources balanced with a serious, visible attempt to be efficient."
– Charlie Lakin

Waiting lists:

- People with disabilities are living longer, and caregivers are aging. Nationally, 30% of parents of eligible individuals living at home are over the age of 60. Only 1/6 of people living at home use paid in-home supports.
- In many counties waiting lists, though required by statute, are not current or accurate. They change constantly, as some people leave and others enter, making them difficult to maintain accurately.
- Waiting lists don't include families who don't know about services, don't know there is a waiting list, or choose not to get on the list. Some people are on a waiting list because the services they are receiving are not the ones they want. Some people have their names on many lists as a strategy for "hedging their bets" with a system they don't understand and can't influence.
- It's too easy to add someone's name to a waiting list and then accept that as an answer, though with self-determination that doesn't make sense anymore. Putting someone's name on a waiting list is not building a self-determined plan.
- Family members say that once on a waiting list, there is no way to track progress. Because people in emergency situations take priority for services that become available, they may wait a very long time.
- We don't have adequate ways to capture what happens to cause families to leave a waiting list. Knowing more about this could help us see what patterns of assistance address particular issues that families face.
- Several court cases helping to define waiting list issues generally send the message, if you're going to have a Medicaid program, you can't have a waiting list. Reasonable access isn't 14 years.

"I'm concerned about getting locked into one model, that everyone has to move out of his home. I want to be sure we have models for people staying in their home, where they get some supports, and they aren't just thrust entirely on their parents' resources. You think, what's going to happen when I die? You look to put your child someplace. That's not the only model."

"In our county a man has been on the waiting list for 8 or 9 years. He's moving up on the list, but only 3 people have moved off the list in 4 years. How much longer is it going to be? While he was waiting, his mother enrolled him in a home ownership class and helped him get a low-interest loan from a bank to go buy his own house. He might end up moving out of his mom's house without the county board doing anything other than connecting him with resources. We ought to take that kind of approach and do it more broadly."

"My son was on a waiting list. We were tired of waiting on a waiting list. We didn't see anything on the horizon, so we went out and got him a place to live. The system didn't respond to my son, it responded to my going out and doing it."

- Conference participants

Roles and responsibilities:

- County boards have become the mainstay of where people go to get services. The entire community thinks the county board is the place to go to get services.
- County boards have witnessed dramatic change over the last 5 years. It's uncertain how they are going to be doing business in the future.
- County boards may be afraid to open the door and ask, "How can we help you?" fearing that responses will place overwhelming demands on local money, since one of their jobs is to protect that local money. County board staff may be afraid of creating a false expectation, if they plan to solve a problem but the plan fall apart.
- Many states are creating fiscal intermediaries, which act as a business agent for people and maintain accountability for funds. Sometimes intermediaries help people decide where to get services. Pilot sites in Ohio's RWJ initiative are not using fiscal intermediaries as they are used in other states, though the Delaware County Board functions much like a fiscal intermediary. In Knox County a financial manager spends about 4-12 hours/month per person handling tasks a fiscal intermediary might do.
- Providers, without a cost of living increase in years, struggle to find staff to provide services and experience rapid turnover. They spend money training newly recruited staff, who then find work at higher wages.

"We're learning from the self-determination process that some families were really reluctant to identify what their needs were, because there was a lot of mystery around how much services cost. We finally laid out a dollar amount. Once people could see a pot of money, we saw a lot of families saying, 'You spend THAT MUCH on my child? Gee, I could spend this money in a whole lot better way to meet the needs.'"

– Conference participant

The will to change:

- People whose lives are most directly affected by change have a relatively small voice in how resources are used.
- All stakeholders in the system have a stake in using resources more effectively and equitably. This is not just one group's problem. It's not a bureaucratic issue, it's a human issue.
- Knowing the extent of the waiting list is essential. Without good information, those who go to the legislature to report on this problem, when asked, "How big?" have to say, "We don't really know."
- Failing to respond to waiting lists could ultimately lead to very active, contentious engagement between people who have services and people who don't, something we've been able to avoid until now.

Changing investments:

- As the world changes, people want different things. In the past, parents were not encouraged to have expectations or to dream what the future could be for a person with a disability. Many younger people and their families have learned to dream about lives of good quality in the community. Some families do not have the energy or knowledge of resources to make the things they dream about happen.
- Many families don't know about the range of opportunities that is now available. They are likely to think about group homes as they were decades ago. For many families, then, choice means choice from a short list of possibilities, mostly the county board's menu.
- Many people who live in congregate settings want to live in the community, and those numbers are building.
- Some people now have an option of an individual budget but don't have a group of people to support them and help them figure out what else is available outside the services that they're accustomed to.
- There is more flexibility within current funding streams than is generally used. Increasing flexibility will require some rule changes, but some flexibility is a matter of attitude change. There is a tendency to make rules, go to the rule book and do things by the rule. Every time something succeeds, it becomes its own bureaucracy, and then people have to figure out how to be creative and get out of that system again.
- The ICF/MR mindset has a tendency to infiltrate all types of Medicaid programs, including individual waivers. Even Supported Living, with all the good intent of its creators, has in many places become regulated and bureaucratic. Delegated nursing rules have the potential to constrain supported living by superimposing a medical model

“People who were raised in their communities won't trade their freedom for support. A lot of folks will do without rather than do with what you've got. That may save you money, but it isn't right.”

“We'd better be looking at the kind of money we're spending for people to be dissatisfied.”

– Conference participants

Don's story:

"I grew up on Gracely Drive. I want to move on Gracely Drive. I want to go home for good. I belong on Gracely Drive. I want someone to put me there. I don't want to be in an institution. I don't belong there. I don't want to ever go back."

– Don Kottmyer

"I met Don about 20 months ago. I think what has kept Don going all this time was wanting to go back to the home he grew up in. Don went to Orient in 1966, at the suggestion of his family doctor, and lived there until 1983, when it closed. Before that time he lived in the house he grew up in on Gracely Drive. When he left Orient he went to live in the ICF/MR in Butler County, where he currently lives. Gracely Drive happens to be in a different county from where he currently lives. Don's not a priority for supported living. He's on the service substitution list."

"What Don and I have been exploring for the last 20 months or so is how he can move. Don and I have a good relationship. He's put his faith in me."

"The strategy that we've finally come to is that we have tried to tell Don's story to as many people as possible. Don's story is a compelling one, because he wants to tell it. He feels that his life has been stolen from him in a way. He's communicated that very effectively to a group of people. People are touched by Don's story, in that he has no power, yet he wants to live where he wants to live. That's how he sees it."

"We have told Don's story to various people, including politicians. We have had some help from Rep. Steve Chabot, who wrote some letters. Hamilton County agreed if they did have an opportunity to place someone into Butler County's ICF, they could serve someone from Butler County. They have agreed to serve Don in supported living. That's where things are now."

"I'm not an expert in Medicaid. The strategy we have taken is to pull on the human aspect of the story, that Don has been unable to move. The funds are not portable. He has been living in an institution since 1966. That's 33 years. He's 63. I think it's time for him to have an opportunity to live where he wants to live."

– Dennis Burger

"Issues around portability are all issues of 'stovepiping,' whose money, where, what stream? Conversations about portability inevitably have to get back to the questions: What have we done to ourselves? Have we made our life too complicated? Do we operate the system in a way that money can very easily move with the person?"

– Gary Smith

Possibilities

What people are learning in Ohio and elsewhere

The importance of principles:

- It's important for organizations trying to reinvest in people's lives to have a value set guiding how they think about what they do. That's still missing in a lot of places in the state.
- Basic Medicaid principles such as statewideness and reasonable access are good ones to have our system structured around. There are other principles, such as separating housing from services, that assist people having real choice.
- What's new and different about self-determination? People have authority over money. Value, outcomes and quality judgments are determined by people themselves.
- Kansas has been working on system change for about 7 or 8 years. The central change in Kansas was expressing that the purpose of their system is to support individuals, not to have all kinds of programming. A massive investment in Essential Lifestyle Planning has been at the center of this work. They set up Community Developmental Disabilities Organizations and gave them money in a flexible way. Kansas helped people leave public institutions, large ICFs/MR and nursing homes by using Essential Lifestyle Planning. They stopped seeking any kinds of services in ICFs/MR, as a matter of policy.

Public resources should supplement, not supplant, the resources of the individual, family and community. Public resources are used most efficiently when people have support to increase their productivity and income, so they can maximize their self-support. Relatives, friends and communities should be able to contribute without fear of penalty, such as loss of essential public support

Public resources should be allocated fairly and equitably to eligible individuals. People should have access to public resources based on need. Through reduction of unwanted and inefficient services, assistance should be available to those who are now waiting for services. Each eligible person should have a known allocation of public funds.

Public resources should be directed by the individual in whose name they are spent and the individual's allies. The individual, with support from family, friends, personal assistants and other allies, should decide how public funds available to them are used. While they may not actually handle the funds directly, they authorize all expenditures. They should receive help to increase their knowledge about possibilities, as well as consumer and management skills.

– *More Than Good Intentions*, Removing the Mask, 1998

Shifting investments:

- Some states have eliminated a lot of “stovepiping” and have one way to move money. For example, Vermont has a waiver program that now offers 3 services: supporting people where they live, getting them a job, and providing some professional services.
- A number of states have recently submitted waivers with spending caps of around \$10-25,000. Supports are based on person-centered planning, emphasizing family support and supported living. By stopping liability, they allow people to have a lot of flexibility in how they use funds. They don’t have to have rules to prevent people from doing things that are too expensive.
- In a number of states, this type of waiver has been a successful response to growing waiting lists. One of the worst things about being on a waiting list is getting little or no support. Across the country family support is typically \$3000 a year, while out-of-home supports are available at \$30-40,000 a year. Some states are introducing new waivers to offer something between those two levels. It’s been more feasible to address waiting lists when the potential liability is \$20,000 rather than \$50,000.
- Many states now have one waiver for people who live with their family and another for people who need more intensive supports. One doesn’t substitute for the other.
- Colorado has a broadly defined service in two waiver programs, one called Comprehensive Services, the other called Support Services. Support services has a hard cap of \$25,000 and average expenditures of around \$10,000 per person. The community agency receives money on a per person, per month basis, and for this they are expected to support the individual appropriately. Knowing that there won’t be cost overruns, it has been possible to give permission for innovations such as microboards. This waiver has seen enormous growth.
- Pennsylvania, as part of a commission to reduce the waiting list, has a new waiver capped at \$20,000, which provides personal support and a personal agent. The personal agent does not have to be a certified case manager, just someone the person and family have confidence in, someone to help figure things out.
- Most states that have made significant progress on waiting lists brought a comprehensive plan to the legislature that balanced both new money for people who are waiting with concrete efficiencies and creativity.
- New Jersey advocates presented legislators with a plan to reduce the waiting list from 5000 to zero over 13 years with \$380.5 million in new money. The plan includes converting ICFs/MR to waiver settings in order to realize some cost savings and making a long-term commitment to the self-determination project.

“ The most remarkable thing about the waiver program is that there’s such a high volume of change to them. They are not permanent. Some states have waiver programs that have been amended 15 or 18 times in 3 years. The principle is, if something doesn’t work, the people who are encountering that it doesn’t work can say so and get it changed.”

– Gary Smith

Anderson v. Cellucci

- In April 1999 Massachusetts residents who are waiting for services filed *Anderson v. Cellucci* (the latter being Governor of Massachusetts) in the District Court.. The case has not yet been decided.
- The logic of the case is this: Massachusetts has opted to provide ICF/MR services to people with developmental disabilities. Once it accepts that option, it is required to provide ICF/MR services to all Medicaid-eligible people with that level of care.
- In addition to ICF/MR services, Massachusetts also provides a statewide waiver program. From the Olmstead decision it would be a short step to say that people with developmental disabilities – if they are judged to do as well or better in community services, and if the state offers community services to some people, and if they do not themselves object to being placed in the community – have a right to community services.
- If the court rules in *Anderson v. Cellucci* that people waiting for services have a right to those services with reasonable promptness, which courts think of in terms of months, not years, then it would follow that people would have a right to both ICF/MR and waiver services, basically at their choice.

- Massachusetts is consolidating underused state institutions in order to redirect savings to the waiting list. With an additional \$37.275 million over 3 years, Massachusetts made an investment in family support and pledged to the legislature to set priorities and serve first people who need services the most.
- Maryland has involved many advocacy groups in generating broad-based support for increased funding, resulting in a commitment of \$118 million over 5 years. Additionally any savings from reducing the population of developmental centers is used to support people who still live at home. Maryland has also made a commitment to children leaving school that they will never be placed on a waiting list. Those who want to live in the community will get assistance to find a job to support themselves.
- In Minnesota the Arc put a face on the waiting list by creating an album of over 100 stories of people waiting for services. Those same people talked with their legislators about what their lives were like, what they needed, and how the investment of years of special education and family support was yielding diminishing returns, because what they had learned was going to atrophy.
- Connecticut is reducing state-run services by privatizing and creating incentives for people to use less-costly services. Connecticut also put a two-year cap on community services, so that savings could go to people who were waiting. There are new, more flexible supports for families with a son or daughter living at home and for people moving from more costly to less costly residential services.

Disinvestment strategies:

- Organizations do manage to get through the process of closing facilities. Generally ICF/MR operators understand the demand is shifting to services and supports. It's important to create a welcoming atmosphere for those who want to step forward and convert. This usually happens facility by facility, by looking at what is needed to help volunteers do that.
 - It's possible to offer ways to deal with property issues to make it easy for providers to convert. Real estate is a local issue. In some places the land is more valuable than the building.
 - ICF rates generally require operators to keep facilities full. In Texas the operator of a 140-bed facility who didn't want to operate it any more negotiated a special rate to keep enough money coming in while phasing down.
-

A story of change in Michigan

[As told by Michael Head]

- In the 1970's we were on track to remodel 11,000 institutional beds at an average cost per bed of \$75,000., which would have bought almost anybody a very nice, accessible home in the suburb of their choice in 1978 in Michigan. We could have solved most of our independent living problems then if we had had some idea about how to reinvest that money. Of course we didn't.
- Starting in about 1980 we had a policy to put all of the institutional dollars under the control of community mental health boards. We were able to redirect dollars out of institutions, because we were responsible for people in institutions. We only have 400 people in institutions now. We had a mental health code that said that people had the right to live in the community and the right to live as independently as possible. We cut off placements into institutions a long time ago.
- Now we've got a wonderful institutional system of 6-bed group homes in Michigan and we have the same kind of disinvestment problem. Smaller homes have become duplexes and are leased back to people who want to live there. Somebody besides the provider owns the buildings. As leases come up, they're going to one-year leases to give people time to figure out how to close a home.
- In the '80's we discovered different ways of doing things through supported living, which we had in 20 counties. This created a core of people who believed in person-centered planning and consumer-directed kinds of things.
- We took the concept of person-centered planning and rewrote our Home and Community-Based waiver in 1994-5 with a number of coverages, including community living supports and supports coordination. Philosophy was the key. Consumer control was part of it. It was an evolutionary process, not different from what you're thinking about. Providers aren't fighting this shift, because they've been changing for a long time.
- In Michigan Medicaid money can be used for a lot of things, because we don't have provider reimbursement tied to service definitions anymore. We have a range of services in which you can cover just about everything, including room and board. You don't have to use licensed providers. You can reimburse mileage and call it transportation.
- Each county board has to have a process for determining quality. It has to involve feedback from consumers and family members. When reviewers go out they want to see what quality improvement looks like, what kinds of things are surfacing, and what kinds of changes are taking place.

“Our [Ohio] county eliminated school and preschool program and moved those funds into portable supported living-type funds, allowing them to draw down more Medicaid and move people where they want to go. The problem is that most counties are still stuck with those dinosaurs that they’re still paying for that in my estimation they don’t have any responsibility running. As long as we continue down that path and don’t bite the bullet and say, we don’t need to be running [schools], other agencies can do that, and move our money where we can utilize it to help people, we’re not going to move very far forward.”

– Conference participant

A story of change in Rhode Island

[As told by Lynda Kahn, Director, Rhode Island Division of Developmental Disabilities; Deb Kney, Statewide Self-Advocacy Advisor, Advocates in Action; Deanne Gagne, Coordinator, Advocates in Action; Doreen McConaghey, Executive Director, PAL]

- Rhode Island is a place where people are actively committed to increasing people’s voice. Our experience has been that as people become more confident talking about who they are and what their personal story is, the lid comes off. People then are able to speak up more about what they want and really advocate on their own behalf, and that is changing the shape of how we do things.
- In 1988 there was an initiative that allowed anybody who qualified to receive \$7000. in General Revenue dollars. They wrote an individualized plan, and because there were no other rules around that, people could write about anything they wanted. It was our first experience with individually directed services. That helped move us forward.
- We had about four years’ experience with another individualized budget adventure, Community Supported Living Arrangements (CSLA), a Medicaid-reimbursed program. Part of what we learned with that experience was the opportunity for people to write a plan. The idea was that people would write about it from their personal perspective and not worry about how we were going to categorize the money and the funding. It was up to the state office to classify things in categories.
- When CSLA happened, families felt that they were much more an equal player at the table and were more encouraged to help set the direction and create the policy. It hasn’t stopped. Now we have a lot of families who are expecting the system to respond to how they and their sons and daughters want it to go.
- There are no more ICFs/MR in the state of Rhode Island. Our entire system is funded through the Medicaid waiver. We are very bound to that system and have kept trying to push the rules and the flexibility of that. We’ve asked the federal government to change some of the Medicaid rules for us. Instead of separate funding streams, which Ohio has now, there would really be a single funding stream.
- We want to make sure we aren’t just talking to people about the money. What’s important is the partnership of what’s possible, how you expand people’s expectations, and how you make sure that folks and families get enough support to sustain the energy it takes right now to get it done.
- The only money we’ve really put out there has been to mobilize the self-advocacy effort and aspects of the parent effort. It can’t happen without those other partners, and that’s made the big difference. Making things understandable to families and people with disabilities is extremely labor-intensive and the best work there is.

Nancy's Story

Nancy Henn is independent on her job, where she delivers messages and navigates around the building where she works. She is known as the most productive worker in her department. A supported employment organization honored her with an award for personal achievement. She recently got a new job microfilming through a regular posting of job openings.

A more traditional view of Nancy might portray her as someone with severe behavior problems, who communicates only with signs and a communication device. According to her father Joe Henn, "If we can figure out how to support Nancy, we know we can support anyone."

Her parents Joe and Marilyn have full authority for the support Nancy receives in all areas of life. Joe and Marilyn decided to get Nancy a car, so she wouldn't be limited in her job and life possibilities. They set up a home for her with three other young women. They wanted Nancy to establish her own home while they were still around to support her. Joe says, "I've got to get to the point where Nancy can go on without me, where I can retire."

Nancy has one-to-one support staff all day, every day. At work a job coach helps with development of new job skills and provides external behavior management support to help Nancy's employer feel more secure. Marilyn selects all support staff and insists on hiring only people with the aptitude to support Nancy properly. Her parents have a letter of understanding with the provider regarding staff selection, MUI procedures and other critical matters. "Nancy's situation is so unusual," explains her father, "we can't delegate management."

Nancy has an individual budget for all aspects of her support. Joe acts as her fiscal intermediary. It takes 5-10 hours a month to keep records, report, pay bills, and keep up with the 5 checking accounts required to make everything work. He receives county board funds and disburses them as needed.

The costs of Nancy's supports are no higher than if she were served within the county board system. What makes her situation work is that the resources are directed by and used for her to maintain a high quality of life.

Joe and Marilyn bought Nancy's car and have an agreement to recapitalize it, so that they can buy another one when it's needed. A foundation paid 70% of the cost of a second vehicle for the home. The local housing corporation owns and maintains the home where Nancy lives. When an IO waiver became available, her parents decided it was time to work with the county board of MR/DD. "We do everything we can before we go to the county for help," Joe says.

Making the money work is "a never-ending struggle, not a done deal." For example, when Nancy was laid off, her unemployment and PERS were counted as resources, leading to two exhausting federal appeals. It has proved challenging to find out where to go to fund each part of Nancy's support plan.

The county board of MR/DD administers Nancy's Individual Options Medicaid Waiver that covers home staff support. The county board also facilitated contact with BVR, which put money in when Nancy came out of high school and when she was between jobs. The county board of MR/DD makes up the difference between expenses and other revenue. Nancy's father maintains documentation and gives the county board a yearly reconciliation. The county board's share of this arrangement has never exceeded what they would have spent for traditional services.

Nancy receives SSI and has a PASS plan in place. When her family looked ahead, they saw 4-5 years for Nancy to get stabilized at work and designated her earnings for a job coach. Eventually earnings at union scale will render her ineligible for SSI. Food Stamps supplement living cost. Family contributions help with clothing, recreation and prescriptions. Joe emphasizes that Nancy pays more taxes than she receives in SSI and Food Stamps. He says, "The government is a beneficiary of Nancy."

“In Ohio we do something that’s very simple, very nonbureaucratic and family-centered and family-oriented, and that’s Family Resources. If there’s any way to take all these stovepipes and direct them into one big vat, I would make it that. Make it all Family Resources, or let me follow the four rules of Supported Living. What you’re talking about is trusting people and paying for things that people ask for and want. We’ve got certain basic underpinnings of that”

“It is impossible to be successful at this without a very strong commitment to family support. Every family that hangs on for another year because of something you’ve helped them with provides resources to serve another person. That’s just good economics, if you don’t believe it’s good humanity.”

– Conference participants

Family as the foundation:

- A good foundation would be to offer families enough resources and enough information that they can begin a creative process. The best way to help is not to overwhelm them by giving them categorical programs but to let them know there are resources.
- Ohio’s Family Support Collaborative has developed 10 principles of family support. The collaborative is developing recommendations to take to legislature, based on gaps, not just in the MR/DD system, but in all systems that touch families of children.
- When families understand that anything they don’t need immediately will be used to support other families who need the money, families are willing and generous.
- Family Resources and Supported Living as they currently exist can be models or paths to follow or demonstrations of how it might work.
- “Family Resource Services, Supported Living, Individual waiver services and Supported Employment provide much more flexible funding... Family Resource Services is the most flexible money available but is in the shortest supply.”
– *More Than Good Intentions, 1998*
- Butler County has been trying to figure out how to use Family Resources or something like it to make funds – \$8,000 to \$12,000 – available to a family, so that they can issue the orders for how the money is to be spent.
- In Minnesota there was going to be a closure of a private facility that had existed for some time. People built around that closure something called the “Futures Fair.” Organizers invited people to come in and talk about different resources, including Fannie Mae, a home choice project, an outdoor adventure program, and integrated vacations.

Agenda for Change

Simplify the system

- **Go after a single funding stream and commit to it**

“Pursue all resources for individualized funding. Review and identify state and local funds that can serve as match to maximize Medicaid funds. Define Medicaid waiver services to maximize individual choice, control and flexibility. Amend existing waivers to include supported employment. Look to local levy funds for maximum funding flexibility.”

– *More Than Good Intentions, 1998*

“The biggest perceived or actual barrier is the idea that the funding is categorical. If it indeed is inflexible, let’s make it flexible. If it’s perception, let’s clear that up.”

“I think we need to funnel everything into a simple program. Let’s make it one we have in existence, maybe with some modifications.”

“We can use Family Resources or Supported Living as they exist in our structures now as models or paths to follow or demonstrations of how it might work.”

– *Conference participants*

- **Reduce barriers in rules and regulations we’ve put in our own way**

“When we first got involved in self-determination, one of the first things we did to try to clarify self-determination was to take a look at all the IO waiver rules, the Supported Living rules, the Medicaid rules. We really looked to see whether the county board made rules when there really isn’t any rule there. What were our own rules that were impacting us? It’s an enormous amount. We would argue even among ourselves. People who had been there a long time would say, that’s a state rule, and it really wasn’t, it was something the county board made up for some reason or another about 10 years ago. It was folklore that became fact.”

“We learned to become very vocal both locally and at the state level when we find something that is a block, to get it changed. Sometimes you’ve got to take a risk and go against the regulations because it’s the right thing to do. That’s scary, but a lot of times if you can say, this works, let me show you how it works, it provides proof to say, let’s make that change.”

– *Conference participants*

-
- **Look at where we can be flexible now in day-to-day decisions**

“Help people use the flexibility that already exists.”

– *More Than Good Intentions, 1998*

“There’s flexibility already available in Medicaid that we can use.”

“We can think about problem solving as we did *Try Another Way*.”

“Don’t ‘what if’ things to death. Solve problems as you come to them.”

“We’ve got to keep our finance people in the mix, because they have to understand this stuff. They can come up with a million reasons from afar why you can’t change things, but at the table they can be among the most creative about how to get stuff done.”

“This way of doing things is good business.”

Reinvest in things that work

- **Be honest about how money is invested now and how far we have to go**

“It’s so complicated in Ohio it’s almost mind-boggling. There are so many interests out there that are fighting for a little piece of the action.”

“The state is in a position right now, from what I hear, to make the right decisions and go in the right direction. But we’re part of the problem, because we say, we don’t want to do that, we don’t want to understand Medicaid, we don’t want to give up our other programs, and we don’t want to give up our ICFs/MR.”

“If we haven’t heard anything shocking today, we’re not representative of people out there in the counties.”

– Conference participants

- **Shift resources from approaches that don’t support community life to those that do**

“A longer-term investment in building the community’s capacity to support its citizens means getting other people into the lives of people we care about, so that somebody’s there saying, ‘What did he really say he wanted?’”

“We should emphasize real-life priorities, like relationships with personal assistants and having a personal vehicle for transportation.”

– Conference participants

- **Begin to divest from congregate programs and facilities**

“Develop mechanisms that encourage the investment of public dollars in people’s lives. Help people with disabilities increase home ownership. Use individual budgets to address personal transportation, including the purchase of a personal vehicle, if necessary. Help people acquire equipment and supplies needed to establish a business or gain employment.”

– *More Than Good Intentions, 1998*

“There’s no magic answer to the capitalization dilemma. The philosophy of self-determination will outlast facilities.”

“What are states talking about when they lay out a plan for their legislature? They talk about hard choices, converting community ICFs to waiver settings. There are skirmishes over that.”

– Conference participants

- **Begin to sort out the roles: What is the county board going to be?**

“We don’t have classrooms. We have no more workshop. We contract that out. CAFS is a dinosaur we need to get rid of at some time and totally convert over to the IO waiver.”

“County boards can take the initiative to talk with individuals and families about the disadvantages of the services they operate. Otherwise the system will reproduce itself.”

– Conference participants

- **Let go of the old ways of doing business, including old relationships with providers**

“Look how contracts are handled – 50 pages and nobody understands what they say!”

– Conference participants

Invest in a workforce for the future

- **Collaborate on recruitment, training and retention of good staff**

“We have to involve DD Councils, state agencies, Arcs and providers working together to elevate the status of this kind of employment. It involves working with providers and technical colleges and other organizations to develop opportunities for people to be trained in these areas in ways that lead to 4-year degrees, arguing for public service scholarships for people.”

“Provider groups say their biggest concern about turnover is not direct care, it’s middle management.”

“When families hire their own staff, staff tend to stay longer.”
– Conference participants

- **Make sure ground-level staff know about money and understand how it works**

“We hire staff that are very competent. Initially we had to deal with a lot of things that staff were afraid of. They were the ones that were dealing with individuals and individuals’ families. They’re not going to sell something that is against their own personal well-being.”

“Managers may not have authority to do all of what’s needed. You start where you can start and jump in with both feet.”
– Conference participants

- **Use staff resources wisely**

“We only have one classification of employee right now and that’s a service coordinator or case manager. There is nothing else.”

“In today’s labor force and the labor force of the future, it’s important to pay people a lot and use them very efficiently.”
– Conference participants

Budget around individuals, not programs, facilities or groups

- **Forge ahead, get people individual budgets**

“Replace congregate care rate setting with individual budgets. Devise user-friendly mechanisms for converting the resources now tied up in facilities to individualized supports. Encourage and support research designed to develop ways that funding can follow the person.”

– *More Than Good Intentions, 1998*

“It’s enormously helpful to people if they know how much money they’ve got. It also keeps people in Medicaid agencies from worrying that costs will go skyrocketing out of control.”
– Conference participant

- **Learn to trust people to handle money**

“We have protected people from the opportunity to be responsible.”

“It takes people time to learn about exercising authority. It’s possible to offer education and training as a waiver service to help people figure out how to manage their own supports.”

“People are not going to go out and do something weird with money, if your arrangements are set up in ways that you can account for it.”

“Interestingly enough, the people we found got involved first in self-determination are the people who are dissatisfied with what they’ve got. If you’ve got people who are beating on your system, if you can’t solve their problems, you might want to think about how can you give them more control of the money.”

“It makes sense to provide people with tools to help with money – CPAs, bankers, lawyers, vouchers.”
– Conference participants

- **Make person-centered planning central to decision-making**

“What makes \$20,000 or \$35,000 work for the individual is the planning that you do. You know what you have to work with, and you know that you’ve got to go find extra dollars. You use that planning process and the circles of support that you develop to go find those other resources, but you’ve got at least a base to work from.”

“It’s important to find better ways to understand what people want, not defined by category of service, but by ‘what is important to you.’”

– Conference participants

- **Focus on value, not just cost**

“If you start thinking about money as a way to get value and improve outcomes and not just how much you’ve got, you’re getting at the idea of equity, and you’re getting at the idea of how to reinvest the dollars.”

– Conference participant

Make friends with Medicaid

- **Master the Medicaid system**

“I work with states developing waiver programs. The last thing I want to talk about is what the rules and regulations say. I want to talk about, what do you want to accomplish in somebody’s life? How can you make that happen? You build the waiver off of that.”

– Conference participant

- **Form working partnerships around Medicaid**

“We need a better partnership with Human Services. We’ve got to bring more people into this conversation.”

“We’ve all got to be sitting at the table, including people with disabilities. We’ve got to develop a strong partnership with Human Services and start talking. They’ve got to come far, and we’ve got to come far, it’s got to be a two-way thing.”

– Conference participants

- **Review and amend current waivers to promote person-centered ways of doing things**

“Deregulation of Medicaid in Ohio would have beneficial effects on providers, which would free up Medicaid dollars. It would also reduce people’s tendency to interpret and reinterpret what the regs say in a variety of ways.”

– Conference participant

- **Respond proactively to HCFA**

“Let’s not overreact to the HCFA audit. We’re not going to get anything done if we stop the flow of IO waivers. We need those waivers now. Those are the best things we’ve got to promote person-centered planning. We’ll not close anything without them.”

– Conference participant

- **Use more state and local money as match to bring in more Medicaid dollars**

“We could eliminate our waiting list and have money in the bank, if we could draw down more IO waivers. We’re committed to spending local dollars on supported living, and we could save 60% of that. Waivers and supported living are interchangeable, as far as I’m concerned. The rules are interchangeable. We have people complaining about the documentation, but once they learn how to do it, that conversation goes away, and all of a sudden they’re asking us for more support dollars, because we’re doing so many things that are so rewarding.”

– Conference participant

Recommendation 24. We recommend Ohio’s MR/DD system expand its participation in the Medicaid Program to maximize the amount of federal dollars available for services.

– Ohio Mental Retardation and Developmental Disabilities Vision Paper, 1999

Respond to people who are waiting for support

- **Use both data and stories to define the problem**

“Laying the foundation involves capturing data about who is waiting and what they are waiting for. We need this foundation in order to engage decision-makers and legislators. Without that kind of information you can build all the emotional commitment in the world and it’s going to be a struggle to get people to respond. That foundation on which you build credibility as well as commitment is being recognized around the country as being more and more important than we had ever guessed.”

“Although accurate data is essential, decision-makers need to have a story and a face to connect with. We can create opportunities for those who are waiting to tell effective stories about the impact on their lives of waiting for a needed service. This puts a face on the issue when talking with decision-makers.”

– Conference participants

- **Tell people where they are on the list and what this means**

“There’s nothing more lonely and discouraging than being on a waiting list and not knowing where you are, not knowing what that list means, whether you’re forgotten, whether it will ever mean anything to you.”

“It is impossible to plan without a timeline. Often that answer isn’t going to be one that people want to hear, but it’s far better that they know than if they try to live their lives with no sense of when the wait will be over, until the phone rings with options that are far less than they would have likely chosen if they had had a better opportunity to plan.”

“You could be next on the list. In the next 3 years if there are 10 crises, you’re not next, and you’re not getting rewarded for planning. The way our list works, I don’t know why you would plan, because you’re better off if you’re in an emergency than being on the list. Those spots are being taken by those who aren’t planning at all.”

– Conference participants

- **Support people while they wait**

“We can help people think more broadly and deeply about what they really want by inviting people to share creative strategies they have discovered for meeting their needs and planning for their future, to say, ‘Here’s what we figured out to help our son or daughter. We think it’s helping a little bit.’ Waiting a bit can be a good thing if the time is used to think things through more carefully.”

“We could work together to increase the funding for Family Resources. Sometimes a relatively small, flexible investment can negate the need for placing a name on a waiting list.”

– Conference participants

- **Engage people who are waiting as partners in finding solutions**

“Ohio’s response to the waiting list problem is likely to require new ideas, new money, and a commitment to examine the use of existing resources.”

“We could increase the variety of things available to people, so they have more choice and discretion about how to get themselves off the waiting list.”

– Conference participants

Shift power from systems to people

- **Challenge myths about funding**

“It’s important to have information about the regulations. There are a lot of misconceptions about what the rules and regulations say. Sometimes they are used as an excuse for not doing things. We haven’t gone back and taken a look at whether it really prevents us from doing something.”

– Conference participants

- **Help people understand what’s possible**

“County Boards or parent and self-advocacy organizations could offer regular opportunities to get the message out about the range of opportunities available and currently being used by people and families in the area. It would be interesting to test the notion that if more families knew about other options for places to live, fewer might be requesting “group homes”, or requesting placement on a waiting list.”

“Make the power shift to people with disabilities, so they can buy what they really want. Give people the power to vote with their feet.”

– Conference participants

- **Involve more individuals and family members in more forums where policy issues are discussed**

“Power and voice need to be very strong with families and individuals.”

“People with disabilities have learned not to go against power represented by boards.”

“If you don’t have written policies and procedures, it’s all folklore. That’s not fair to individuals and families. Write policies down so that everyone commits to live with them. It makes things more real.”

– Conference participants

Enlist families as partners

- **Support families to help them begin planning**

“We often speak a different language from parents. Service coordinators may be entrenched in a system. They start talking about ‘community outings’ and ‘peer recreation’ and ‘socialization’. The parent doesn’t understand what they’re saying. When you start getting into funding and money and where you spend it, it’s even worse. One of the things we’re doing in our system is working hard to eliminate all that different language, so that people will be able to understand what we’re talking about.”

“We can involve families in planning and managing money by helping them learn about costs and patterns of spending.”

“We ought to make sure families receive information that helps in selection of providers. Results of provider reviews should be available to families.”

“Why not ask, ‘If we could do something for you, what would it be?’ and then do it?”

– Conference participants

- **Work with families to expand the range of what’s available**

“Many families who have come through integrated public education will be looking for different things. Behind Nancy [Henn] is a ‘human wave’ of the PL 94-142 generation that will call on county boards to become something different.”

“Other parents could do what Joe and Marilyn Henn have done, but they might need training and assistance.”

– Conference participants

- **Identify and remove the disincentives families face as they plan for the futures of their sons and daughters**

“Remove barriers and disincentives for individuals and families to use personal resources for both costs of living and support costs.”

– *More Than Good Intentions, 1998*

“Many obstacles face those who want to share resources and property with their offspring. Families who want to design creative supports that allow interesting days and safe places for their sons and daughters to live also face barriers. When these obstacles are ones we invent through state and local rules and regulations, we ought to find ways to change them. When families have prevailed and discovered new possibilities, we can hold these examples up for all of us to see.”

– *Conference participant*

Recommendation 27. We recommend developing a public policy by which families with resources may contribute some portion toward funding their family member’s needs.

– *Ohio Mental Retardation and Developmental Disabilities Vision Paper, 1999*

- **Support the Arc’s initiative to get more money for Family Resources**

“Substantially increase budgets for family support services. Use Family Resource Services to draw down Medicaid whenever possible. Plan with families to use family support dollars in the most effective, efficient ways to support the family, now and in the future.”

– *More Than Good Intentions, 1998*

Build the political will for change

- **Create a visible political presence**

“You saw what happened to us in the last budget process. We had about 80 people at the hearings. This was the first time MR/DD has showed up to tell their story in about 10 years. We’d better come back the next time with about 8000 people and get some attention. 80 won’t do it. I don’t care how many stories you have. Numbers equal voters. We’d better start working now.”

“People at OMB and other areas of state government have to understand why changes are important. We’ve got to bring them along.”

– *Conference participants*

- **Help people prepare for the political process**

“We can bring the people together who are going to make the biggest difference in terms of getting the legislature to respond to this problem, and that’s parents who are the concerted force that in earlier years created every service we have. We can bring them together for information, inform them on what’s going on, what is our status and what is the budget. How nice it would be if the county board weren’t hosting those, if it were a parent organization or a self-advocacy organization.”

“If the Department sent all 88 counties a message in a very strong way, then the taxpayers would get it and the families would get it.”

“Those engaged in these activities should know that battles with the status quo are inevitable. A strategy that relies on new money to resolve the waiting list problem will not be enough. The states with the most advanced waiting list approaches attempt to use new dollars plus other strategies that are attempts to be more efficient with current resources.”

– *Conference participants*

- **Help people speak about the need for change**
“It would be helpful if people were angry and would express their anger in directed kinds of ways, to say, this isn’t working for us.”

“The self-determination expansion offers new possibilities. One is to use the \$500 incentive payment to connect some of those people who have experienced individual planning and individual budgeting with people on the waiting list. The money could be used to hire someone to facilitate futures planning, which generates more connections and resources. Or maybe use \$100 of that to meet with their legislators and talk about waiting list issues.”
 – Conference participants

A message for ODMR/DD Director Ken Ritchey and ODHS Director Jacqui Sensky from conference participants

- Get input from others, including county boards, before making changes;
- Begin deregulation of Medicaid in Ohio, which would free up Medicaid dollars and reduce people’s ability to interpret and reinterpret what the regulations say;
- Extend deregulation to other programs;
- Go after a single funding stream, moving away from our current approach of “stovepiping” the funding;
- Use HCBS services such as supported living and family resources as a model for support;
- Eliminate ICFs/MR and give people in ICFs/MR the right to choose something else and have money follow them;
- Review and amend current waiver regulations to promote person-centered choices, with language that clearly says the person has control over hiring and firing;
- Try not to overreact to HCFA audit;
 - √ Pick the right issues to fight with HCFA about;
 - √ Don’t create our own moratorium on new waivers;
- Person-centered planning should influence/drive regulation, not the other way around.

- **Use Vision Committee statements on self-determination to advance the message**

Recommendation 8. We envision an Ohio system that promptly furnishes to all who desire and are eligible a residential setting of their choice and one which allows them maximum independence. We further recommend that sufficient funds be allocated for this purpose.

Recommendation 9. We envision a system of supports and services for families that are identified as such, that are directed by consumers and their families, and that are adequately funded and flexible.

Recommendation 22. We envision a State in which adequate financial resources will fund appropriate supports and services to all persons who need them.

Recommendation 25. We recommend the Ohio Department of MR/DD provide for a review of the current MR/DD reimbursement system.

Recommendation 26. We recommend that funding mechanisms be flexible and responsive to consumer choice.

– *Ohio Mental Retardation and Developmental Disabilities Vision Paper, 1999*

Postscript: What's happened since the conference?

- In November Tom Nerny, of the National Self-Determination Project Office, and Robert Gettings, of the National Association of State Directors of Developmental Disabilities Services, spoke to staff of ODMR/DD and ODHS about self-determination and Medicaid.
- Also in November Don Kottmyer moved to Gracely Drive in Cincinnati. A series of health scares proved harrowing for Don and his allies, but eventually resulted in treatment of long-standing health problems. Dennis Burger reported, among other things, "He has a physician that seems interested in helping him.... Don went to his sister's house last night and she decided 'to keep him for a few days'. ...He seems to like being there." Don loves being back in his home neighborhood and spends holidays and free time with the good friends who helped him escape.
- HCFA's report of Ohio's Residential Facility Waiver was released in draft form on December 23, 1999. It included findings related to health and safety and presented 24 recommendations for change. Several are especially pertinent to this report:
 8. ODHS must work to expand service options across the state so that waiver consumers have the freedom of choice to select their residential and day program providers and so that new providers can participate in the waiver program.
 23. ODHS should amend the waiver to reflect the true number of people it can serve.
- The Ohio Department of MR/DD recruited an additional 26 county boards of MR/DD for its self-determination expansion, bringing the total number of participating counties to 30.
- In December the Ohio Department of MR/DD distributed an Information Notice on waiting lists that includes the following provisions:
 - > IO waiver and RF Waiver services are established as separate categories of service, giving individuals living in ICFs/MR access to waiting, rather than service substitution, lists.
 - > At least annually county boards are to communicate with individuals who are waiting to determine whether service requests have changed and to let people know their current status on the list.ODMR/DD is also requiring county boards of MR/DD to submit a roster of individuals who are waiting for waiver services by April 20, 2000.
- Ohio has begun developing a plan for compliance with the Americans with Disabilities Act as outlined in the U. S. Supreme Court's ruling in the *Olmstead* case.
- The Arc's Waiting List Campaign held a series of public forums in several locations around the state. These events featured testimony about the impact of the waiting list on individuals' lives.
- Stella Gola, who attended the conference, organized a study visit to Rhode Island to examine collaboration among family members, people who receive services, providers and public organizations. A team of family members, people who receive services and county board staff made the trip in January and will be using what they learned there to launch a self-advocacy effort and to support family members to become better advocates for changes in policy related to funding.