

## **LEARNING FROM EXPERIENCE**

**Rights Won by Parents and Consumers in the Mental Retardation and Developmental  
Disabilities System and Lessons Learned for Parents and Young People in the Child  
Welfare System**

by Hilary Russ November,  
2004

Prepared for the Child Welfare  
Fund and the FAR Fund of the  
Fund for Social Change

## Lessons Learned

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This report was supported by the Child Welfare Fund and the FAR Fund administered by the Fund for Social Change. We would like to thank Mike Arsham, Steve Holms, Ellen McHugh, Beth Mount and Allen Schwartz, who read drafts of the report. We wish to extend our sincere gratitude to all the people who participated in the forum, in particular those who shared their personal stories.

Fund for Social Change

- Child Welfare Fund
- FAR Fund

666 Broadway, Suite 830

New York, New York 10012

David Tobis

Executive Director

(212) 529-0110

[David.Tobis@nycwf.org](mailto:David.Tobis@nycwf.org)

## **Executive Summary**

On April 28<sup>th</sup>, 2004, about 30 people came together in a forum convened by the Child Welfare Fund and FAR Fund of the Fund for Social Change. They were there to discuss decades worth of reform in the mental retardation and developmental disabilities (MRDD) system and child welfare system. But the participants – including parent activists, self-advocates, funders, lawyers, an Office of Mental Redardation and Developmental Disabilities (OMRDD) administrator, non-profit leaders, and social workers – weren't there to pat themselves on the back for all the hard-fought laws they managed to get enacted. Instead, they outlined the methods and techniques they had used to win rights they once feared they might never get. And they were there to pass those lessons on to advocates working to change the child welfare system.

A dozen panelists spoke about a range of issues, including the history of abuse, and the epic fight to end that abuse, in New York's disabilities system. Other discussed parent support networks, racism, and the lack of rights for families in the child welfare system. But everyone was working towards one basic goal: for the child welfare community to learn how the MRDD community created permanent legal entitlements and consumer rights by weaving them into the very infrastructure of the system.

With that goal in mind, we present ideas for future work for both communities. These ideas could form a base for further dialogue to provoke systems change that would empower consumers. The Child Welfare Fund and FAR Fund would be interested in supporting initiatives that try to implement some of the following recommendations:

### **For both communities**

- *Create alliances between advocates and consumers in both systems.* These groups and systems have begun contact, but they should strengthen existing ties and create new ones. This could be done around a specific issue that would benefit from a cross-systems approach, or through long-term planning.
- *Establish methods by which consumers will feel safe to complain.* In the developmental disabilities system, the service plan review, bill of rights, board of visitors and other policies are supported to insure that people in the system can speak out about abuse and still feel safe in their residences. Yet often, they do not. And in the child welfare system, few of these safeguards exist. Advocates and administrators must determine exactly why, where, when and how consumers feel threatened so can

- they work towards establishing more effective – or more readily enforceable – methods of keeping people safe from retaliation.
- *Define the trade-offs of working within and from outside the system.* Among advocates, this should be an open topic of conversation. Each group should try to carve out its own, consistent position in relation to the system. It should also hold dialogue with groups who maintain different positions relative to the system. An overall strategy for change in each system should take the different positions into account.
  - *Raise salaries of direct service staff.* Front-line staff be properly paid for the very difficult, emotional and important work of caring for our friends and loved ones who are vulnerable to abuse due to their age, disability, or lack of rights. Advocates should push for more money for direct service staff on the local, statewide, and national levels.

#### **For child welfare advocates**

- *Create a legislatively approved bill of rights to parents and young people.* Such a bill – one that mirrors the far-reaching, tangible bill of rights written into state law for people with disabilities – would require legislative action. Therefore, child welfare advocates and consumers should begin to target sympathetic legislators who could bring this kind of bill forward in New York State and City. One that happens, groups of foster children, mothers fathers, grandparents, foster parents and other advocates could travel to Albany to pressure legislators for support.
- *Establish a Parent to Parent phone support system.* New York State’s OMRDD funds Parent to Parent, enabling a parent whose child has a developmental disability to receive personalized telephone support service from another parent. An individual or group interested in starting a similar parent-run, phone-based network in child welfare system should study existing Parent to Parent models, seek out advice from its leaders, develop a pilot program, and approach city and state government agencies for funding and support.
- *Help develop and promote legislation to form a Board of Visitors, which could inspect facilities and records.* The Board of Visitors in the developmental disabilities system advises the governor directly. It has extraordinary access to facilities and can,

without any forewarning, inspect a residence or other facility's physical conditions and records when reports of abuse surface. Advocates and sympathetic administrators ought to seek out politicians who would be interested to begin work on legislative action to bring a Board of Visitors to life in the child welfare system.

- *Form new collaborations and bolster existing ones between parent and youth organizing groups.* This might be done by forming alliances specifically for this purpose, or by dedicating a position on a group's board to members of another group. Parents and kids struggling to change the system should brainstorm methods that will allow them to work better together, or at least side by side, and to remove the wedge the child welfare system drives between them.

### **For advocates for the disables**

- *Discuss whether there should be on-staff or independent advocates.* This was a topic of some debate at the forum. Currently, OMRDD facilities do not use a reliable system of internal abuse reporting. Some forum participants thought it would be a good idea to have an in-house advocate, but others thought a person in such a staff position could be easily co-opted. An independent ombudsman is an alternative worth considering. Consumers, advocates, administrators and others in the developmental disabilities system should pursue how to protect people with disabilities who are dispersed throughout the city in community or non-community residential placements.

## **INTRODUCTION**

On April 28, 2004, about 30 people came together in a forum convened by the Child Welfare Fund, the FAR Fund, and the Fund for Social Change. They were there to discuss decades worth of reform in the mental retardation and developmental disabilities (MRDD) system and the child welfare system. But they weren't there to pat themselves on the back for all the hard-fought laws they managed to get enacted. Instead, they outlined the methods and techniques they had used to win rights they once feared they might never get. And they were there to pass those lessons on to advocates working to change the child welfare system.

The invitational forum, which took place in a conference room at the Open Society Institute, quickly surpassed a typical policy discussion. Several participants shared personal, often painful stories about their own entanglements with the disability and child welfare systems. They illustrated the emotional cost these systems can exact on their clients and the need for further reforms based on the input of clients themselves. What's more, they elevated the event to an emotionally-charged, frank and open discussion so engaging that almost everyone stayed until the very end, when it ran out of time.

Participants hailed from both systems, and they included parent activists, self-advocates, funders, lawyers, an Office of Mental Retardation and Developmental Disabilities (OMRDD) administrator, non-profit leaders, and social workers. Some of them have been working in their respective systems for a few years, others for decades. A dozen panelists spoke about a range of issues, including the history of abuse, and the epic fight to end that abuse, in New York's disabilities system. Others spoke about parent support networks, racism, and the lack of rights for families in the child welfare system. But everyone was working toward one basic goal: for the child welfare community to learn how the MRDD community created permanent legal entitlements and consumer rights by weaving them into the very infrastructure of the system, superseding the funding whims and personal style of any one particular commissioner.

With this goal in mind, the discussion opened with a run-down of similarities and differences between the two systems. Numbers tell part of the story: the New York State Office of Mental Retardation and Developmental Disabilities had an annual budget of more than \$2.9 billion in FY 2004-05 (the OMRDD reports, though, that there are millions more spent beyond that with federal matching dollars on other services, like transportation). It serves about 135,000 people across the state. Many are served through its New York City Regional Office, which coordinates four Developmental Disabilities Service Offices throughout the city. Citywide services are also administered separately through the Department of Health and Mental Hygiene. But for the disabled in the city, the state has significant impact on their lives.

The state Office of Children and Family Services has an even bigger budget. With \$3.6 billion, it supervises foster care facilities, oversees adoptions, is responsible for about 2,000 children in its custody in juvenile residential facilities, administers services to others and more. But it's mainly the Administration for Children's Services, a city agency, that serves kids in New York City. It's annual budget in 2004 was \$2.1 billion. It used that money to run child protective services, to provide foster care for about 21,000 kids in 2004 through contract agencies, and to provide preventive services, directly or through other agencies, to 29,000 children.

But beyond numbers lay complex issues that grow out of policies and out of a long history of inequality. Consumers in the child welfare system feel that they're seen as the unworthy poor, unlike the disabled, who are considered worthy poor. Then too, though disabilities affect all social classes and ethnic groups, the disabilities system clearly serves a great many people of color and people in poverty. But it's practically an oasis of diversity compared to the child welfare system, which serves almost exclusively people of color – 95 percent – and low-income New Yorkers. That means the MRDD community has a multi-racial, multi-ethnic, multi-class base for consumer mobilization – a base that simply doesn't exist with the same breadth among child welfare clients. Even so, advocates like Vaulda Kendall-Browne say that black and Latino families (in both systems) don't get enough information, and what little they do get isn't delivered quickly enough.

The most distinct difference, however, is perhaps the most important: the rights of consumers in the two systems are wide apart. Though forum participants say consumers' rights in the Empire state's MRDD system are behind those in some other states, they're light years ahead of those allotted to clientele in our child welfare system.

The rights laced into the fabric of the disabilities system include:

- ♦ A legislatively mandated bill of rights
- ♦ The right of an individual to challenge his or her service plan in court
- ♦ The right in many cases to control the level and degree of family/friend participation in a consumer's life
- ♦ Client control over how government funds for his or her care are spent (financial self-determination)
- ♦ A state- and federally-funded Developmental Disabilities Planning Council, one-third of which are consumer members, that helps draft policy
- ♦ A Board of Visitors that can visit facilities without notice and inspect records

Of all the rights for individuals, “the most important is the right to appeal any decision that's been made at several levels,” says advocate Steve Holmes about the ability to challenge service plans. “It's often a way that decisions are overturned.” Even so, New York's OMRDD is not nirvana. The person-centered planning it has been promoting doesn't always work in practice, and the system still needs beefed-up protocols for reporting abuse and other improvements.

Consumers of the child welfare system have the right to attend their service plan reviews. But that's about it. There's no legislatively mandated bill of rights, no ability to appeal elements

of a case plan. There's no Board of Visitors and no government-mandated consumer advisory panel. There's certainly no financial self-determination. Yet hurdles remain for both communities. To look ahead to possible goals that can guide future work, it's useful to first look to the past to see how far advocates have come.

## **BERNARD'S STORY**

Imagine what it would be like if you couldn't take good care of yourself due to a physical disability, and that it landed you in a state-run institution. Then imagine that at that institution, there was only one staffer for every seven patients, including you, and that caregivers could get away with mental, physical, and sexual abuse. Bernard Carabello didn't have to imagine – he suffered beatings and other abuses for nearly two decades at Willowbrook State School on Staten Island, the institution made infamous by investigative reporter Geraldo Rivera. As Carabello recounted some of these bad old days at the forum (such as unnecessary medical procedures, like prescribing an enema and aspirin for what turned out to be appendicitis), it was difficult for participants to listen with dry eyes.

Parents of patients at Willowbrook saw only what the director allowed them to see. Some parents, including Carabello's, only visited once every five or 10 years, which made it easy to let the wretched conditions go unnoticed for so long. "Every Sunday I used to sit by the window to see who'd visit me," Carabello says woefully. "When three o'clock came, I was always disappointed. When they did come, they were never allowed to see what went on behind closed doors, [because] we visited in the day room." Because "inmates" often had to sit around naked, he remembers having to steal clothes from others for some of these visits.

He's haunted by other memories of degradation as well: "They used the same wash rag for all of us, or the one to clean the floors." The abuses, both large and small, played a great role in dehumanizing residents, he says. "You lose your identity. You're not Bernard, not Johnny or whoever. You become a number. They used to take a magic marker and write our names on our arms or backs to make sure we didn't get lost."

When he was only an infant, Carabello was misdiagnosed by doctors, who told his immigrant mother that he was mentally retarded (in fact, he has Cerebral Palsy). The doctors suggested institutionalization, and Carabello wound up in Willowbrook, where he would languish for the next 18 years in the company of almost 6,000 other patients.

In the early 1970s, Jane Curtin began exposing abuses at Willowbrook in her articles for the *Staten Island Advance*. But when Geraldo Rivera took cameras inside the institution in 1972,

a furor erupted. Viewers saw images on their televisions of scores of children, naked, restrained, unsupervised, sometimes sitting in their own excrement – warehoused.

The photos sparked instant outrage, suffusing an already burgeoning movement for disabled rights with energy and generating the political will for enactment of local and federal legislation. By the time Willowbrook’s doors were shuttered for good in 1987, the landscape had shifted radically. Activists, attorneys, nonprofits, agencies, and government would all have a role to play.

## **LEGAL AND LEGISLATIVE LANDMARKS**

It has been a long struggle to win better conditions and more rights for the disabled. In the 1960s, President John F. Kennedy, and later his younger brother Bobby Kennedy, took a deeply personal interest

in promoting rights for the disabled – and both backed up their interest with action.

But it wasn't until the 1970s – the decade some have called the “golden years” of the disabled peoples' rights movement – that some of the greatest advances were made. The decade produced four major legal and legislative events, as outlined at the forum by Allen Schwartz, the bureau director of planning for the New York State Office of Mental Retardation and Developmental Disabilities.

The first change came in 1971, when the Nixon administration passed Medicaid Title 19, which established federal standards for care. That's because when it agreed to use Medicaid dollars to support institutional care in the states, the federal government set out guidelines for the size of those institutions and the quality of care their clients received. In order to meet the new standards, overcrowded, understaffed institutions were forced to downsize. Now, clients saw the first improvements in their quality of life and services.

The improvements were followed up by Judge Frank Johnson Jr.'s decision in *Wyatt vs. Stickney* in Alabama. Originally brought in 1970 by hospital employees who feared they'd lose their jobs to the shrinking state budget, the case morphed, centering instead around services and conditions – it's hard for workers to provide adequate standards of care when there aren't enough of them. As the case ground on, Judge Johnson, along with the Justice Department and associations for the disabled, helped draft the Wyatt Standards that were to guide implementation of the declared right to treatment. The Standards called for humane psychological and physical environments, qualified staff in adequate numbers, individualized treatment plans, and the provision of services in the least restrictive environment. “*Wyatt* is perhaps one of the most influential cases not decided by the United States Supreme Court, one which has shaped the course and development of mental health law in the United States and beyond,” wrote Clarence Sundram, former chair of the New York State Commission on Quality Care for the Mentally Disabled. Indeed, at the forum, Schwartz articulated how this class action law suit, one of the first to succeed in the area of disability rights, prohibited involuntary commitment and required treatment instead of punishment by formulating its standards for care. The 33-year-old case was closed in December 2003, when Judge Myron Thompson decided that Alabama had finally complied with the last settlement agreement.

Yet the fight for rights continued on other fronts. Section 504 of the Rehabilitation Act of 1973 outlawed discrimination by the U.S. Department of Housing and Urban Development against people with disabilities. While this act itself left a lasting impact on policy, several delays in passage of the act, mostly due to Congressional inaction, also enlivened the disability rights movement. The delays frustrated activists who were pushing for passage of the act, and that

frustration culminated in some of the first sit-ins and shut-downs of Washington buildings on behalf of disabled people. “It spurred on the early advocacy organizations to become much more aggressive,” said Schwartz in a follow-up interview. “It was the precursor to what we see today, with the civil rights dimension to disabilities advocacies.”

Finally, the year 1975 saw several important pieces of legislation enacted. Congress passed and President Gerald Ford signed Public Law 94-142, then called the Education for All Handicapped Children Act but later re-authorized in 1993 as the Individual with Disabilities Education Act (IDEA). This landmark legislation guaranteed a free public education for developmentally disabled kids – and one that utilized the least restrictive alternative. “This was the first law that gave parents the sense that their kids had a right to an education,” Schwartz noted. In fact, he said, the ARC movement – chapters of what were originally known as associations for retarded citizens – started “because parents in the 1950s stayed home with their kids who had been thrown out of school, and they took out ads in papers to find other parents.”

Also in 1975, the landmark Developmental Disabilities Assistance and Bill of Rights Act was passed. Among other things, it established mental health legal services and protection and advocacy systems, such as adult protection services to investigate abuse. It also set up developmental disability planning councils, which, using federal money, are small systems change councils, like governors’ planning councils, whose stated goal is to spur innovations and improvements in the system. The act even allowed for research, rehabilitation, and training centers tied to universities in every state.

In New York state, the Willowbrook case, filed three years earlier, finally settled on a consent decree in 1975. That established steps and standards for care for the disabled in the state. About two decades later, to try to begin to end the case, the parties went back to court and negotiated a permanent injunction, which meant the standards were lessened slightly but that members of the class can be discharged. That created an exit strategy – one that will probably not be fully realized for years to come.

Over the past 25 years, the number of mentally or physically disabled people warehoused in institutions has plunged from TK,000 to under 1,000. “The laws – and the funding they generate – are important building blocks,” said Schwartz at the conference. Professionals were less effective than everyone else at pushing changes forward. But there were plenty of other actors: by using the media, constitutional rights, legislation, class action suits, and stakeholder group action, advocates were able to make disability rights into civil rights.

## **GAINS MADE**

Consumer rights and input in the MRDD system in New York aren't implied. They're not whispered or gossamer. They're concrete. That's because the rights of the family are enshrined in policy, said Roberta Mueller, an attorney with New York Lawyers for the Public Interest, at the forum.

There is, for example, a section of New York's Mental Hygiene Law (section 633) that is essentially a consumers' bill of rights which must be observed by any facility receiving OMRDD funding. It includes, among other things, the right to live in a safe, secure environment, free of abuse. Clients have a right to express grievances without fear of reprisal, a right to medical care, and many other rights.

According to this section of the regulations, disabled people also have a right to object to their written plan of service, and to have a hearing to put those objections on the record. The procedural nature of this particular right is what allows the other rights to be manifested concretely in someone's daily life. A person could object to any number of things – prescribing psychotropic drugs against his or her will, not getting enough community involvement, not being protected from harm by lacking a one-to-one aid, or not seeing the dentist often enough – and challenge them with an official hearing when negotiation on the case plan fails. “Anything you could express as a right, an intrinsic right, can be effectuated through this hearing process,” said Mueller by telephone.

This kind of procedure allows a client to hold an agency accountable – on the record and in writing. Even so, some of the rights break down in practice. The consumer's lone voice at the table, with no veto power of its own, is not always enough to counter several experts who might show up to a hearing, and so the state often wins such procedures. But, noted Mueller, many of the rights (to adequate food choices, for example) are also “things that OMRDD's quality assurance people look for when they go in and do an audit.” So the enforcement of rights is “not entirely dependent on people bringing objections to their plan of care.”

The work of Mental Hygiene Legal Services provides some assurances of compliance, too. Created in 1964, MHLS is a state-mandated, state-funded, specialized legal services program for people who live in residencies paid for by OMRDD or the Office of Mental Health, and to those in a Home and Community Based Services waiver program (which allows Medicaid recipients to receive services in the community instead of going into an institution), as well as those who receive OMRDD services. Lawyers work on many different kinds of cases, including

as court appointed counsel for commitment hearings for mental illness. But they also provide direct representation for disabled people who are challenging their service plans.

Throughout care, the role of the client is supposed to be central. A disabled person can regulate – by blocking, inviting, and managing – her family’s involvement in her life. Even that family involvement is regulated hierarchically. First, for example, an agency might go to the individual herself, or to her guardian, to make an important decision or get consent. Then, perhaps, it would approach her spouse, and then a parent, child, or sibling. There’s also room for actively involved friends in the hierarchy.

Disabled people in New York also have self-determination. That means, essentially, that they control where money is spent for their care. They determine the course of their lives through their budgets, usually through a fiscal intermediary. Individual facilities, therefore, do not get government funding for individual clients unless that client chooses to spend the money there. The idea of financial self-determination took off in the mid-1990s, culminating in principles of self-determination and in a National Center on Self-Determination. Advocates for this approach even managed to get passed an amendment to the Developmental Disabilities Act to mandate direct funding for self-advocacy groups.

Consumer rights have been woven into macro level policy processes, too. The Developmental Disabilities Planning Council is a state- and federally-funded advisory council. One-third of its members are consumers, either disabled people or their parents. They review regulations and help draft OMRDD’s annual plan for services. Compared to the child welfare system, there are many more points at which high-ranking state officials must sit face-to-face with consumers, listening to them “at a very grassroots kind of level,” said Mueller. “That’s just kind of built into the statutes.”

In addition, at least a minority of members of the OMRDD’s Board of Visitors must be parents. In this capacity, they can inspect without notice any community residencies and review records. The access has proven invaluable for keeping institutions in line. Recently, for example, a Board of Visitors member alerted Mueller and others to proposed changes at a local developmental center. The center was planning to re-open a number of beds for disabled children coming out of foster care. To make sure the new units didn’t constitute a permanent institutional setting, advocates, through members of the Board of Visitors, were able to ask questions about who would be moved there and whether placements would be permanent (they turned out to be temporary). Advocates were able to ensure that kids weren’t simply being re-institutionalized. In addition, it served as grounds for cross-system advocacy between the disabled and child welfare communities.

But by way of comparison, the child welfare system is still light years behind. There's no bill of rights, no hearings to dispute specific elements of a service plan CK. And because of who they are, there's no political will to help parents, said Jessica Marcus at the forum. She's a staff attorney with the family law unit of South Brooklyn Legal Services. The law, she said, is clear about not separating families because of poverty. But in family court, over and over, reunification is delayed because a family lacks resources – like housing – and can't get mandated services. Cases are adjourned for months on end. She said, with obvious disappointment, "We're close to where people in the developmental disabilities system were in the 60s."

## TACTICS FOR CHANGING AND LIVING

### From routine to radical

As advanced as disability rights may seem today, the struggle began just as many other fights for social justice start – as a grassroots, segmented, loosely arranged affair that came to employ many different tactics along the way. Here are a few important ones that forum panelists and participants discussed.

Lobbying Capital Hill, Albany, and City Hall has long been a mainstay of making change. Getting legislation passed – legislation with real teeth – was one main tactic used by advocates for disability rights. Along the same lines, rallies and demonstrations helped put pressure on elected representatives when legislation came up for discussion in the halls of government. But more aggressive methods were also employed. Radical direct action has been used for years by both handicapped people and their parents, who had to learn how and when that kind of tactic is appropriate.

Diana McCourt remembers such actions. Parents whose children, like McCourt's, were locked in Willowbrook, held covert meetings with staffers, lawyers, disability experts and other longtime political activists. They decided to hold a sit-in on Victory Boulevard, the highway that ran in front of the institution. About 25 people stopped traffic, and the local press, who had been called ahead of time, were on hand to cover the act of civil disobedience. McCourt doesn't recall any arrests – the sit-in took place more than 30 years ago. But she remembers feeling apprehensive. "It was scary being there, doing that," she said of the Victory Boulevard sit-in during a telephone interview. "Most of us were not politically active people."

But that didn't stop them from taking other direct action. Around the same time, they also tried to take over the Statue of Liberty (with only about 10 activists in a sea of French tourists, that action wasn't quite as successful). They also broke into administrative offices at Willowbrook, stealing keys so they could let in reporters to document conditions there.

Using radical direct action meant harnessing intense anger, the residue left after frustration with the system and with life itself had bubbled up and frothed over. "We had justified rage," fumed McCourt at the forum. "There had been decades of reform attempts. We were fed up, and we were ready to go all the way." But such intense emotions must be transformed carefully. "Anger can entrap you and control you," McCourt warned in a telephone interview. "Unless you can transform your anger into action, you're stuck. In the early days, it gives you the burning fuel to be active." But later on, she admitted, she's had to do a lot of personal reflection

and hard work to not let the anger take over her life. She realized she couldn't help her daughter effectively unless she got control over her anger. She still struggles with it today.

To bolster themselves whenever they felt uncertain, and to figure out what kinds of action to take, Willowbrook activists looked for guidance from a handful of steadfast mentors – two doctors, three social workers and later, an attorney with the American Civil Liberties Union. These mentors possessed broader political and social outlooks than the parents had yet accumulated. From other activists in the country and overseas, they dug up models for supporting people with mental retardation in their own communities. And their mentors were the ones who developed relationships with the media and other civil rights activists and lawyers.

But the civil rights movement wasn't the only one to inspire McCourt and other activists. "Nothing about us without us" was the motto for the South African disabled movement, and it's often repeated in the U.S. among disability rights advocates. It has prompted advocates and the disabled to attend budget hearings, legislative sessions, local council meetings, and individual agency policy conferences. "Any time and any place that decisions are being made that affect the lives of people with disabilities, people with disabilities believe that they should be part of the process," Steve Holmes, administrative coordinator of the Self-Advocacy Association of New York State (SANY), said by telephone.

That kind of attitude evolved into today's self-advocacy movement, fathered in New York by Bernard Carabello, who founded SANY in 1986. Conceptually, the self-advocacy movement in the United States mirrored work already underway in Scandinavia. That's according to Holmes, who spoke at the forum along with SANY advisor Tony Phillips, who relayed his personal experience. Not one to miss the opportunity to crack a joke, Phillips noted that "self-advocacy starts when you're a baby, when the doctor hits your bottom." When you start wailing, "you're telling him 'Hey, what are you hitting me for?'"

On the local level, a group of 10 to 20 self-advocates form a chapter, coming together to learn how to speak up and often engaging their service provider organizations. Most local groups have some organization structure, such as a president, vice-president, and advisor. SANY is the largest organization of its kind in the country, with 150 of these local groups as members. Regionally, the local groups come together, often to do more systematic advocacy around regional offices of the OMRDD and city or county councils. They also do state-wide self-advocacy, and there's a national organization as well.

## **Emotional tactics**

Because physical and mental disabilities can extract such a heavy toll on people and their families and friends, establishing emotional supports continues to be a key tactic in maintaining personal and political health. Nowhere is this better exemplified than in a Circle of Support. The term, said Phillips at the forum, refers to “friends who you talk to when you need them. You build on relationships – that’s what it’s all about. They understand you.”

For parents of disabled children and adults, creating structured support systems used to be an ad-hoc process. Ellen McHugh recalled how, after searching by herself for information on her son’s deafness, she finally found the right resources – from an AT&T operator. That operator, she recalled, gave her more useful information than the hospital that had mis-diagnosed her son with “withholding language.” In particular, after she got connected to the New York League for the Hard of Hearing through the operator’s referral, she received a phone call one day from another mother looking for help with her own child’s deafness. The connection provided McHugh with a sense of relief. “It made my life look real to be communicating with other parents,” she remembered. “The experience of being pitied by outsiders was horrendous.”

That kind of personalized telephone support is how Parent to Parent works. It’s a 25-year old program that offers one-to-one emotional support from parents, to parents of the disabled. Parent to Parent began in New York at the behest of Marie Goepel and other parents who sat on the Advisory Council to the Commissioner of OMRDD. They had gotten wind of a program in San Jose, California called Parents Helping Parents. After taking an exploratory trip to study the program, parents on the Advisory Council recommended to OMRDD that a similar program be established in New York. So between 1993 and 1995, the ground was seeded with chapters of Parent to Parent setting up shop in Buffalo, Albany, and Staten Island around the same time that the idea was exploding nationally.

Because parents are connected to each other for a common goal and through a single issue, differences like race, class, gender, income, sexuality, and ethnicity can fade into the background. “You have an identity that crosses all lines – the disability,” said McHugh at the forum. According to Parent to Parent literature, when a new mother, father, caretaker, grandparent, foster parent, or guardian is referred to a local Parent to Parent office, he or she is matched to another support parent, sometimes within 24 hours of referral, based on factors like a similar type of disability or family issues. The “veteran parents” who provide the support receive some formal training before they begin volunteering, and the parents coming into the match receive a host of invaluable, unique supports: someone to provide information about community

resources and about the disability itself, and a friend who will listen and understand through first-hand experience what they're coping with.

When a child is diagnosed with a disability, the initial lack of information and the emotional twists can be entirely overwhelming. Parents have to learn not only about the disability their child has. They also have to decipher medical, legal, financial, and special education jargon, try to find appropriate social and other services in labyrinthine systems, deal with friends or relatives who distance themselves out of fear, and try to gauge what impact these changes will have on the rest of their immediate family. That can leave parents trying to keep their heads above water in a sea of turbulent emotions, ranging from guilt, anger and depression to numbness, loneliness and confusion. Trying to negotiate these feelings while fulfilling stepped-up logistical needs for a disabled child, in addition to the daily demands from the rest of the family, can leave parents with no spare time to gather information or meet their own emotional needs.

That's where Parent to Parent comes in. Some of the programs are new and small, with fewer than 10 parents, while some are more than 20 years old and serve hundreds of families. Most are organized by volunteer parents, and as such are extremely low-budget, and fewer than half have a paid coordinator. Much of the work is done by phone. The matches that result can be short term, helping a parent find information for his or her immediate needs. But for some, the relationship turns into a lifelong friendship, providing years of aid that cannot be duplicated by professionals or support groups.

One more emotional tactic, storytelling, is used informally by both disabled people and parents. It allows them to be expressive while also bridging the gap between themselves and lawmakers, other parents, administrators, and even the general public. The emotional vetting of storytelling helps shore up the person telling his or her tale. In addition, it establishes group identity, conveys news, builds connections, and gets across points in ways so powerful that outsiders, politicians, and administrators can understand them on a whole new level. That's according to McCourt, who talked about her daughter, Nina Galin, at the forum. Nina's autism and mental retardation landed her in Willowbrook from 1971 to 1976. By talking with other parents and sympathetic staffers, McCourt was able to play a major role in shutting down that institution when her daughter became the lead plaintiff in the Willowbrook lawsuit. Thirty years later, storytelling keeps the history of that struggle alive.

Such stories have become documentation in legal cases. They have also helped the movement create its own vision. Storytelling led to a common cause, said McCourt. With stories, "we were creating a separate identity and defining where we wanted to go. We circumvented the system. We avoided diluting and compromising our mission." Finally, storytelling also opened up

## Lessons Learned

the forum itself, drawing participants into the lives of those who were willing to share very personal struggles, adding immediacy, intimacy and emotional weight to the discussion.

## **Relationships**

Telling personal stories is an integral part of building relationships among not just parents and the disabled, but between them and system administrators. When people listen and talk to each other – in particular when administrators get to know people with disabilities on a personal basis – it is system discourse. Sometimes a little grease is needed alongside advocacy. Schmoozing, especially with officials and administrators, is a favored tactic of Joey Perez, former board president of SANY. “It’s ‘let’s have lunch,’” said Holmes by telephone. “It’s a real informal dialogue. The walls go down.” Holmes has seen how often, when officials first meet disabled self-advocates, they harbor a host of preconceived notions about disabled people. It’s likely very similar for parents of children – and the children themselves – who’ve been swept up into the child welfare system. But schmoozing can break down those misconceptions in short order. In the disabled rights’ movement, at least, real change slowly simmered as administrators and self-advocates got to know each other on a personal level.

Ultimately, system dialogue and change was pushed along by people like McCourt, Carabello and Phillips who used their stories to bear witness. At the forum, with her glasses perched on the tip of her nose and eyebrows arched, McCourt said, “Our task was to instill fear and doubt in the intransigent opposition. To the mothers and fathers it was common sense. To the professionals and the lawyers it was revolutionary.”

## **WITHIN/WITHOUT**

Advocates have been arguing, cajoling, negotiating, and celebrating with administrators in the MRDD system for decades now. After all that time working together, some of the parties that started out on opposite sides of the spectrum have moved closer to each other than they had ever imagined. That intimacy has, it can surely be argued, benefited the system as a whole. But it has also left some wondering what happened to that radical, outsider energy that pushed change forward in the beginning. In the struggle to hold social systems accountable to their clients’ needs, one major tactical question looms large: is it better to work from within or without, to be partners or adversaries with system administrators? The answer: both.

A partnership approach has made gains over the long term, steadily whittling away barriers to communication and antagonistic feelings that can impede beneficial compromises. As proof of the success of this approach, Allen Schwartz pointed to the evolution of work following the Willowbrook consent decree. The decree initially established a review panel of nine experts

who came to New York from other states to direct services. But they “were highly critical. It was a time of great adversarial posturing,” said Schwartz after the forum. “There was a lot of back and forth doing plans, having plans criticized, going to court.” In the 1980s, the panel was defunded and replaced by a special master, who turned to more congenial methods. Later a commissioner’s task force took over, and now it meets quarterly, doing a host of committee work in a dozen different areas. In the beginning, Schwarz noted at the forum, it had been “a very hostile, adversarial relationship. It has mellowed and we’ve come to appreciate each other. The partnership approach is more productive in the end. We’ve grown up together.”

In the world of organized labor, rank and file union members sometimes feel their leadership grows too comfy with industry bosses over the course of years of negotiations. Similarly, some in the MRDD community feel the partnership approach might be giving away the power of a strong point of opposition. Some groups may even believe this position is inherently antithetical to their founding missions. Debate around the issue of working from within or without had only just begun when the forum ran out of time. Said one participant, who works in the disability community, “There’s very little vilification in the system. Saying ‘where’s the common ground’ involves trust. In building relationships, you do lose something – maybe a little edge is lost.”

Ellen McHugh referred to *On War*, a small book that left a big impression on her approach to dealing with the MRDD system. For those who view themselves as working from outside bureaucracy’s door, she recommended a few particular lessons from the book: 1) never underestimate your adversary, the person with the control, 2) don’t walk away mad and 3) never arm your enemy – “don’t let them say yeah, that’s a crazy parent,” joked McHugh.

In practical terms, though, both approaches are needed. Without activists who are willing to take radical stances, and without the strong emotions they can harness and engender in others, it can be tough to fuel movement forward. Eggs don’t fry without fire. Yet once those groups manage to spark outrage about conditions, rights, or other issues, there has to be someone “at the table” to take their message directly to commissioners and other administrators and to do the tedious work of negotiating and implementing bureaucratic changes. Even Diana McCourt, whose anger spurred her to sit-in on highways and historical monuments and break into institutional offices, says “it’s important to be able to negotiate, not just to be out in the street raging.”

“They’re not necessarily mutually exclusive,” said moderator and host David Tobis. “Without Sharonne [Salaam] picketing, CWOP wouldn’t necessarily get invited to the table. The extremes define the center.” Indeed, some participants felt it was the relationship between

different groups' positions that mattered. Said Jessica Marcus, "If you're not at the table, be at the door. Have people inside and outside at all times, and respect each other." Others cautioned that civil disobedience and other radical, adversarial tactics should be used sparingly, only as a last resort.

Anne Hardiman, director of member services for the New York State Association of Community and Residential Agencies, said that her group and self-advocacy associations are playing essential roles, and advised participants to "think about banding together." When building coalitions, it might be beneficial to address, consciously and visibly, differences in each others stances and methods of making change.

Then, too, some groups are not invited into formal discussions, arriving at their outsider status more by default than design. "Developing relationships is a tactic, and it works if you're invited to the table," said SANY's Steve Holmes. "But in other states, self-advocacy groups have a tougher time than we do here." They struggle, for example, to score appointments with high level state officials in their systems. "In our state, Tom Maul, commissioner of OMRDD, he's virtually met with our boards 20 times in the past 10 years. He comes to all our parties. Our access to government has been greatly enhanced by relationships." While that's partly the result of receptive government officials, it couldn't have happened without all that schmoozing, or a lawsuit.

## **STATE OF CHILD WELFARE**

New York City's child welfare system may often seem like a Goliath to all the Davids who've tried taking it on. But despite its size and the power it wields over families' lives, it has been pushed and altered – radically so in recent years – to respond to its clients' needs. In this rundown of all the challenges that remain, it's worth taking a quick look at inroads made so far by kids, parents, advocates and attorneys and at the risks taken by policymakers themselves.

Former ACS Commissioner William Bell has supported system shrinkage and even system change. Since the creation of ACS in 1996, the number of children in foster care has dropped from almost 43,000 to about 21,000 in mid-2004. ACS also initiated a reform plan and has made significant progress on many of its stated goals: increasing community-based placement for kids in foster care and boosting preventive and aftercare services. The time it takes to get kids placed with foster families, as well as the time it takes to reunify children with their parents, has

been cut. ACS has sliced child protective workers' caseloads in half, while bumping up the amount of training all case workers receive, as well as increasing their salaries.

Parents and children – the real stakeholders in the system – say they feel more listened to now than ever before. Sharonne Salaam founded People United for Children in 1992 to help advocate for institutionalized children, like those living in group homes or prisons, and their parents. Giselle John, training coordinator for Voices of Youth, spent several years in foster care herself. At the forum, she said “we’re breaking the stereotype that we don’t care. We shake up the room because we have a testimony.” At the forum, Salaam and John both noted that they had made some inroads, wielding more influence than they used to with administrators. “We have the attention of policymakers, judges, lawyers, and commissioners. It was not like that years ago,” said John.

The Child Welfare Organizing Project, started in 1994 as a project of the Education Center for Community Organizing at Hunter College, set out to give parents a greater role in shaping the child welfare system. The organization has helped parents raise their voices in hearings of the City Council, State Assembly, and the New York State Bar Association. They’ve spoken out at professional conferences and public forums and to the media. And they’ve participated in policy discussions with ACS administrators, including the Commissioner, and with members of the Child Welfare Advisory Panel. At a very basic level, CWOP is “a group of people who will act, listen to you, and value your opinion,” said employee Bernadette Blount, a parent organizer, who recalled a time when they weren’t invited to the table at all.

CWOP’s persistence has paid off. For instance, along with State Assemblyman Roger Green, the organization helped write a “Child Welfare Parent Self-Help and Advisory Councils” appropriation into the budget of the state’s Office of Children and Family Services in 2002. CWOP Executive Director Mike Arsham said by phone that he hopes this will lead to “some kind of fiscal and statutory acknowledgment that it’s good practice to encourage family involvement at every level,” similar to other categorically-based service systems like mental health, substance abuse treatment – or developmental disabilities.

Yet inequalities and other problems continue to dog the system. Forty percent of the kids placed in foster care in 2000 came out of homes in three geographic locations: the South Bronx, Central Brooklyn and Upper Manhattan. And it’s a well-known fact that over 95 percent of the children in foster care are African-American, Latino, or Asian. What’s more, these kids often don’t feel safe speaking out about verbal, physical or sexual abuse that they endure while in foster care, and that’s one of the things they have in common with disabled children. One of the biggest problems Giselle John sees in the foster care system is “the inability to speak freely about abuse

and feel safe about it.” More change is needed to solve these problems, and families believe this will only happen once they have real input into both their own individual cases and policy as a whole.

Just look at where client inclusion stands now. Despite administrators’ stated goals of family participation in their own cases, the clients themselves are largely left out of the process, said John at the forum. Parents and kids “sit outside for hours while they draw up a case plan, then you go in and sign it. It’s the same for the courts. Young people wanted to say something, but no one asked. It’s policy developed without asking the consumers.” Besides CWOP and a couple other organizations, she said, families’ voices are still missing.

For example, the law requires New York’s foster care agencies to include parents in biannual Service Plan Reviews, but parents actually participate in them at a rate of 30 to 50 percent (though it has to be noted that just five years ago, the rate was a miserable 10 percent). And less than a third of children in foster care visit their parents at or above the legal minimum – two hours each month! (A Renewed Plan of Action for ACS, May 2001). That’s despite evidence that points to parent participation and qualitative family visits as determining factors in successful family reunions.

“The child welfare system seems to look at people in the system as the unworthy poor,” lamented John. “It’s dehumanizing.” Fola Campbell, executive director of Concerned Citizens for Family Preservation, agreed: “Parents don’t feel empowered,” she said at the forum.

Part of feeling disempowered may stem from a lack of information. John notes that there’s a dearth of information for kids and families in foster care. Part of her aim is to continue spreading the news to foster kids about what their rights and entitlements are. In the meantime, it’s easy to get mixed messages. “Young people are saying one thing and parents another. And then the system says something totally different,” said John. “We call that palao” – a hodgepodge of leftovers thrown into a stew – “a nasty tasting pot!”

It’s no wonder, then – when youth don’t know their rights and parents are excluded from planning their own family’s future – that a sense of fragmentation results. “People in the developmental disabilities community are united. Families in the child welfare system are divided,” said John. Splitting the unit that could most effectively advocate on its own behalf, John believes, is one main reason why child welfare advocates feel they’re lagging behind those in other systems and why far-reaching changes and clients’ rights have progressed more slowly. This even happens on an individual level. The system, said Blount, “is designed to help you and hurt you at the same time. It still boggles my mind how they achieve this balance.”

The child welfare system, then, sometimes seems like it's designed to drive a wedge between the two parties it's supposed to unite: parents and children. The sense of rupture, of disjointedness, pervades both individuals and families. "The biggest problem is getting families back together," said Salaam of PUC. Her organization has sued ACS to get a fairer investigation – or any investigation at all, in some cases – before kids are taken away from their parents. This rift hurts not just families, but also makes it harder for reformers to unite around common goals. Does this pose an even greater challenge to child welfare advocates than to disabilities advocates, because of the more complex family dynamics and the inheritance of a structural impasse from the system itself? "Parents are as victimized as young people – they sometimes feel as voiceless as we do. Yet we don't come together," John said.

## CONCLUSION

We've learned from the experiences of self-advocates, consumers, families and friends who helped alter policies that affect disabled New Yorkers. With the current challenges facing child welfare advocates in mind, we present a few recommendations to help guide future work:

### **For both communities**

- ♦ *Create alliances between advocates and consumers in both systems.* These groups and systems have begun contact, but they should strengthen existing ties and create new ones. This could be done around a specific issue – such as a method to increase consumer safety (see below) – that would benefit from a cross-systems approach. It can also be pursued as part of long-term planning for groups in each of the systems. Greater ties could also be forged if consumers and advocates in each system dedicated time to a few key face-to-face strategizing sessions.
- ♦ *Establish methods by which consumers will feel safe to complain.* Throughout this report, we've seen that the developmental disabilities community has fought for and won several important safeguards in their system. The service plan review, bill of rights, board of visitors and other policies are supposed to insure that people in the system can speak out about abuse and still feel safe in their residences. Yet often, they do not. In the child welfare system, where fewer safeguards exist, consumers also feel that if they complain, they'll be the victims of retaliation. Kids in foster care might fear speaking out about conditions in their

home. Parents are afraid that if they seek preventive or aftercare services, they'll be put under the microscope of ACS or even separated from their children for a longer period of time. In order to create more effective methods of protection, each system must first determine exactly why consumers feel unsafe to speak out and how existing safeguards break down in practice. Only after advocates and administrators learn more details about why, where, when and how people feel threatened can they work toward establishing more effective – or more readily enforceable – methods of keeping people safe from retaliation.

- ♦ *Define the trade-offs of working within and from outside the system.* Among advocates, this should be an open topic of conversation. Each group should try to carve out its own, consistent position in relation to the system through democratic group debate. It should also hold dialogues with groups who maintain different positions relative to the system. Perhaps more importantly, an overall strategy for change in each system should take the different positions into account. All of this work ought to be done in a respectful manner, insuring that the strengths of each group are highlighted and that advocacy proceeds on a more unified front from all angles. The development of new voices and approaches should be encouraged.
- ♦ *Raise salaries of direct service staff.* Front-line staff should be properly paid for the very difficult, emotional and important work of caring for our friends and loved ones who are vulnerable to abuse due to their age, disability, or lack of rights. Without enough staff, or without staff who can adequately provide for their own kids, how can officials expect the direct care of children or people with disabilities to be smooth, safe, and effective? “As a society, we give prestige to the jobs that are more administrative and have the least contact with people,” said Fredda Rosen of Jobpath. “You make money in our field by moving up and getting an administrative job.” Advocates should push for more money for direct service staff on the local, statewide, and national levels. One national group for people with disabilities, the American Network of Community Options and Resources (ANCOR), has begun using media spots to pressure legislatures for higher staff salaries in developmental disabilities systems. It has also worked with the U.S. Department of Labor to develop a pilot workforce development program to recruit and train more direct support workers. Some advocates note, though, that raises ought to be only one fight of many, and that they will not solve all a system’s problems if other spending priorities remain skewed.

### **For child welfare advocates**

- *Create a legislatively approved bill of rights for parents and young people.* Such a bill – one that mirrors the far-reaching, tangible bill of rights written into state law for people with disabilities – would require legislative action. Therefore, child welfare advocates and consumers should begin to target sympathetic legislators who could bring this kind of bill forward in New York State and City. Once that happens, groups of foster children, mothers, fathers, grandparents, foster parents and other advocates could travel to Albany to pressure legislators for support. Such a bill would not be a panacea, however. Consumers do have a few rights, but they are not always enforced. For instance, legal representation for parents and children can be extremely inconsistent. Without continuity and zealotry of legal representation across the board, consumers see their rights go unexercised in the courtroom.
- *Establish a Parent to Parent phone support system.* New York State's OMRDD funds Parent to Parent, enabling a parent whose child has a developmental disability to receive personalized telephone support services from another parent. For the child welfare system, there is no such network. An individual or group interested in starting a similar parent-run, phone-based network in the child welfare system would benefit from similar government support. It should study existing Parent to Parent models, seek out advice from its leaders, and perhaps develop a pilot program and approach city and state government agencies for funding and support.
- *Help develop and promote legislation to form a Board of Visitors, which could inspect facilities and records.* Many social service systems have independent groups that try to monitor care-giving institutions. But the Board of Visitors in the developmental disability system has a different role than a nonprofit advocacy group. It advises the governor directly. It has extraordinary access to facilities and can, without any forewarning, inspect a residence or other facility's physical conditions and records when reports of abuse surface. And because a certain percentage of the Board of Visitors members must be parents or consumers, the system as a whole is made that much more responsive to consumer concerns. Advocates and sympathetic administrators ought to seek out politicians who would be interested in beginning work on legislative action to bring a Board of Visitors to life in the child welfare system.
- *Form new collaborations and bolster existing ones between parent and youth organizing groups.* At times, the child welfare system can take its toll even on successful, strong-willed activists. The family split inherent in the system can get reflected back to the world of advocacy. Advocates for parents in the system and advocates for children in the system should try to strengthen ties with each other. This might be done by forming alliances

specifically for this purpose, or by dedicating a position on a group's board to a member of another group. Parents and kids struggling to change the system should brainstorm methods that will allow them to work better together, or at least side by side, and to remove the wedge the child welfare system drives between them.

### **For advocates for the disabled**

- ♦ *Discuss whether there should be on-staff or independent advocates.* This was a topic of some debate at the forum. Currently, OMRDD facilities do not use a reliable system of internal abuse reporting. Some forum participants thought it would be a good idea to have an in-house advocate on staff, instantly accessible to residents, to take complaints about conditions. But others at the forum noted that when an ombudsperson or on-staff advocate is getting paid by the facility itself, it puts the advocate's job of vigilant reporting at risk of being easily coopted. An independent ombudsman is an alternative worth considering. Consumers, advocates, administrators and others in the developmental disabilities system should pursue how to protect people with disabilities who are dispersed throughout the city in community or non-community residential placements.

The overarching goal is to transform the child welfare system, to have it listen to the voices of families, to make it responsive to their needs. In order to accomplish this goal, advocates must be willing to work together and fight for change. They must overcome the tendency of the system to split the family unit. And advocates have got to analyze who benefits financially from the status quo. They've got to follow the money. Those seeking to change the child welfare system for the better can arm themselves with bigger, better tools – tools they learn from the successes of advocates in other systems.