



# **MODELS OF CLIENT AND CITIZEN PARTICIPATION IN WELFARE PROGRAMS IN THE US**

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## BACKGROUND

The purpose of this policy paper is to identify models of client participation in four social programs and citizen participation in general (citizens-at-large) in the USA, with applicability to the State of Israel. The four systems are child welfare, disability, aging, and public welfare. First, there are some clarifications provided to understand the terminology used in the US; this is followed by the multiple rationales for client and citizen participation (CCP). Then the background and models in the 4 specific systems and the general one are presented. The report ends with a set of pre-conditions that have been found to enhance and promote citizen participation as well as the factors that cause it to fail, and a discussion of the issues government leaders will need to address. Selected references are found at the end, along with attachments (e.g. terms of contract with MOSA).

## CLARIFICATIONS

Because of differences in the size, history and type of society between the US and Israel, there is a need to clarify some concepts or terminology used in this paper

**1) Citizen/Client-** The term “citizen” is used to mean “citizen-at-large;” that is, the involvement formally or informally in civic life of any person residing in the US in their role as citizen. The term “community resident” or “community participation” is sometimes used to refer to a person situated in a place; that is someone who resides in a locality or neighborhood. Client/citizen participation (CCP) will be the abbreviation for the overall topic; otherwise, the particular population e.g. parents, senior citizens, etc. will be used.

The term “client” refers to a person who is served by, eligible for, or receiving benefits from an institution of government such as child welfare client, elderly client, person with a disability, etc. In the US, it is common today to substitute the word “consumer” or “customer” for “client,” or “patient” to imply more autonomy or higher status for the recipient of service.

The term “welfare client” and people “on welfare” in the US has a narrow scope and historically, a pejorative meaning. It usually refers to persons (mostly women with children) who receive public assistance (cash). It is not used for people who receive cash benefits through the US Social Security system; nor is it used for people who receive social services.

**2) Auspice of CCP: Levels of Government-** In the US, “top down” mandates for citizen participation can originate from anyone of three levels of government-national (Federal), State, and local (which refers to either a county or city/municipality). Outside government (“bottom up”) models of CCP derive from advocacy, grassroots or coalition-type organizations.

The mandates for citizen/client participation are usually found in

government documents known as “regulations.” These are issued by the administrative body (department/ agency/ministry) responsible for implementing a law. Regulations usually include rules, procedures and guidelines, but have the same authority as if they appeared in the actual law (Statute or Act).

**3) Organizational Language-** The terms “non-profit,” “voluntary,” and “community-based” organizations (CBO’s) are generally used for those formal organizations created outside government. Those organizations may or may not receive government funding. Some of these non-profit/voluntary/ community-based organizations are also called “agencies,” typically when they provide a service. The terms, “advocacy” or “grassroots” organizations are usually reserved for those organizations which do not provide a direct service to individual people. However, many organizations do both advocacy and service. Typically, most CBO’s or non-profit social service agencies receive some government funding or contracts. Therefore, the line between governmental and non-governmental is increasingly blurred. The term “private” agency in this document also means a non-governmental/non-profit organization. In recent years, there are private profit-making (for-profit) corporations which provide health and human services, and which sometimes receive government funding, such as nursing homes. That line between government and the corporate sector is also blurred now.

### **RATIONALE(S) FOR CLIENT/CITIZEN PARTICIPATION (CCP)**

There are many reasons to promote CCP, both in the form of engaging the citizenry as a whole or the public-at-large, and in the form of involving the clients or consumers of services. Much of the rationale is based on **values and beliefs**. There is little large scale systematic evaluation of the process and outcomes of citizen participation, and there is no one definition or meaning that seems to satisfy all the interested groups. There appear to be three distinct but overlapping rationales that emanate from either or both government and the non-government sectors: *philosophical, pragmatic, and political*.

**PHILOSOPHICAL. Citizen participation is viewed as an essential part of a vibrant democracy as an end in itself.** Citizenship is seen as a triangular relationship between civil, political and social rights and is linked to a reciprocal relationship between the government and individuals. It is based on a belief in self-determination at individual, group and community level. At the micro level, CCP increases self-esteem, self worth and self-efficacy, often labeled “client empowerment.” It builds solidarity and cohesiveness among the participants which leads to group empowerment.. This forms the basis of social networks also called “social capital” which could lead to stronger communities. An involved citizenry also has greater stake in social stability of society; conversely, citizen participation may lessen alienation and isolation (anomie) among excluded segments of society. It has the potential to create trust and cooperation to work toward the “common good”. 7; 14; 22; 32

**PRAGMATIC. CCP is viewed as a financial and human resource investment. It can also increase service utilization and client loyalty.**

Programs work better when people are invested and have a sense of ownership. Agencies and systems can obtain a more accurate and realistic assessment of needs. Involving clients can lead to more innovative programs and processes. Clients and citizens are an additional pool of volunteer support, providing in-kind resources (goods, services, and staff) as well as direct financial contributions and investment. Involved (empowered) clients can move into para-professional staff, board and community leadership positions in traditional and alternative service delivery structures such as mutual aid/self help groups; independent living centers, etc. The term co-production has been used to mean some input into service provision.<sup>15</sup> It links formal services to informal networks and mediating organizations, expanding the pool of assistance available, as well as creating more “social capital”. CCP can reduce dependence on government funding, as well as permit a more independent voice for advocacy and social change.<sup>13; 1; 5;</sup>

**<sup>16</sup>. If the practical is successful, the constituencies can move into the political arena.**

**POLITICAL. Organized CCP can build a power base** by developing an invested, articulate and knowledgeable constituency. It builds leadership and spokespersons for issues and programs. It can create consciousness and a collective identity, with the potential for mobilization. It could also lead to redistribution of resources. With an active citizenry from disempowered communities, it could lead to greater resources for that community, and/or more equitable distribution of resources and power. Clients can have a direct influence on decision-making at the agency and government level through their collective voice. An engaged citizenry may be a willingness to trust in, support, and work with government collaboratively after direct involvement. It makes it easier to hold government institutions accountable, and could minimize conflict within and between communities.<sup>17; 19; 5; 33</sup> . From the government side, CCP could shift the obligation away from full government responsibility to community/voluntary and individual responsibility.

## **GENERAL FEATURES OF CCP IN THE US**

1. No national/Federal law or standard exists that governs CCP in all areas.
2. The US system is a decentralized one, allowing States and localities flexibility in how they implement most laws.
3. The US social welfare system is categorical, rather than universal. Eligibility is narrowly and strictly applied.
4. Historically, the government has been the “last resort” for establishing rights and benefits; most programs originated in the non-profit, voluntary sector (“bottom up”).

5. Concepts such as “deserving” and “undeserving” still apply to most welfare categories. Certain populations and problems are more accepted as worthy of or in need of government support. In this paper, the aged and those with disabilities would fall into the former case, and those who are poor, and whose children are identified by the child welfare system, would fall into the latter.

## **SECTION ONE:**

### **CHILD WELFARE SYSTEM**

#### **HISTORICAL CONTEXT**

No major regulations or guidelines mandating client involvement exist at the national or state level, especially those which require the participation of birth/natural parents with children involved with child protection services. No doubt this is because of the system perspective on parent behavior.

Traditionally, the history of child welfare in the US has been invested more in foster care, residential care and adoption than it has been in prevention programs to keep children with their natural families <sup>1c</sup>. This is consistent with a punitive paradigm where the parent is generally viewed as the part of the problem and not part of the solution. It is also a system with a disproportionately greater percentage of minority (African American and Hispanic) children in care, resulting in its being labeled as “racist” by many critics. It is a system, at least in New York City, dominated by many non-profit agencies. These CBOs contract with the City government to provide a range of services to families and children. They receive financial reimbursement, which has generally favored the removal of children rather than maintaining them in their home or with family members. While CBOs receive most of the government funding, it is the States and localities which have the regulatory and oversight responsibility.

The child welfare system has been plagued with scandals around issues of competency and resources. In the last few years, there have been large scale exposes in several states. And when an occasional horrendous incidence of extreme child abuse makes the headlines in the media, the system reaction is to revert back to one of punishment and control. Only occasionally do those cases result in widespread structural reform that gets at root causes. It is a system, historically where social workers have been both in the leadership and on the frontline as practitioners.. But over the years, in most states, child welfare programs have been under funded and under attack, resulting in deprofessionalization. Those with the least formal education often have the toughest decisions to make. It is not a system generally sought after by professionally trained social workers, although there are government counter-trends now to reorganize and re-professionalize the system. This is accompanied by funding from the Federal government and some state legislatures.

However, the Federal government role in child welfare has varied over time. Federal legislation in the last 20-30 years has focused on standards,

competency, training and information systems to make the child welfare system more accountable. At the same time it has sent “mixed messages” to parents and professionals. On one end, it has provided more funds for prevention of child abuse and neglect, and for family reunification, while on the other end, it has required quicker adoption, permanency planning and termination of parental rights. Natural parents have not been part of the decision-making processes at the planning and policy levels, and only sometimes in their own cases, even when they are required to be part of case planning.

## **CURRENT TRENDS**

Given this historical background, it is not surprising that this stigmatized population of “child welfare clients,” i.e. the biological or birth parents, have not been included as partners and problem-solvers at any level until recently.

In the late 1990’s, with changes in Federal child protection laws including foster care and adoption, the Federal government included the term “consumer” in its standards for State agency planning for the first time. They also mandated Citizen Review Panels to evaluate the extent to which States and localities carry out their child protection functions. The regulations mention in writing that these panels must include members “broadly representative of the community.” Most “bottom up” advocacy efforts have been mainly in the legal arena to gain formal rights for the parents. Well publicized court cases in recent years have put the spotlight on parent needs and wishes to participate

In the last ten years or so, the attitude toward, and treatment of birth parents has begun to change. It has been acknowledged that most children coming into the system are for “neglect” rather than abuse. And there is an increasing recognition that combinations of drug abuse, poverty, domestic violence, welfare reform (which coerces mothers to work), discrimination and lack of child care, all put tremendous stress on families and place them “at risk.” Some leadership at the public level (“top down”) and a growing “bottom up” advocacy and grassroots movement in the non-profit community are shifting the paradigm toward community-based solutions, **and the direct involvement of parents in decisions that affect their lives.**

One private foundation —the Child Welfare Fund (CWF) in New York City—has had a profound effect on promoting parental involvement, youth participation (for those who have been in foster care, residential care, group homes) and other systemic legal, social and political reforms. They were the initial funders of a small grassroots organization known as the the Child Welfare Organizing Project (CWOP). CWOP and a few other “bottom up” CBOs **organize parents, train parent advocates, promote parent rights and mandate parent participation in government-created structures at the planning, policy and evaluation levels.** In the last few years, partly as a result of this outside-government activity, the New York City Commissioner of the Administration for Children’ Services (the City’s public child welfare agency) created a Parent Advisory Council which meets regularly with him. There is also local legislation at

the NYC City Council pending that would require those non-profit child welfare agencies that contract with the City to hire parent advocates as staff, and it would also create a city-wide Parent Advocate Advisory Council.

The other major initiative that will be mentioned in the “citizen-at-large” section of this report, is the **community-based collaborative model**. Partnerships are being established in geographic areas to focus on bringing to the table all the stakeholders who are involved with children and families, including clients, extended families (“kin”) and neighborhood residents. These community-based strategies often involve partnerships between the public and private sector and funders, and are complex, mixed multi-system, -agency, and – discipline structures.

The “top down” and “bottom up” strategies and structures are interactive and cumulative. One response by citizens and clients to a punitive government system is collective organizing and advocacy; this results in government opening the door (willingly or unwillingly) to hear the client voice. Once inside, the clients’ views are heard; new or reformed government agency leaderships listens and might change their philosophy. With continued grassroots pressure and support by professional advocates, there is the possibility of negotiation, and some reforms in the system. This happened in NYC with new political leadership at the elected and appointed level. Although growing slowly, the trend is clear in NYC and around the country, the client/parent voice needs to be heard—and listened to.

## **GOVERNMENT-INITIATED (“TOP DOWN”) CLIENT/PARENT PARTICIPATION CHILD WELFARE MODELS**

**I. NATIONAL (FEDERAL) LEVEL-** Just three references to parent involvement in Federal regulations since the late 1990’s were located.

### **Model A.**

**Advisory Panel to the Secretary of Department of Health and Human Services (DHHS).** The Panel’s purpose was to study Kinship Care and produce a Report on its outcomes. The following words were part of the regulation: “...(The Panel)...shall include *parents*, foster parents, relative caregivers, former foster children...etc.” to review the Kinship Care Report on extent to which children in foster care are placed in the care of relatives.

### **Model B.**

**Administrative Monitoring: Child and Family Service Plans (CFSP).** A second regulation required all 50 States to produce CFSPs. This stems from the Adoption and Safe Families Act of 1997 administered by the Federal DHHS. There is one specific question (Item 38) that asks the States how they involved clients. It uses the following language: "In implementing the provisions of the CFSP, the State must engage in ongoing consultation with tribal representatives, *consumers*, service providers, foster care providers, the juvenile court, and other public and private child and family-serving

agencies, and include the major concerns of these representatives in the goals and objectives of the CFSP."

Information about birth parent involvement in the administrative and policy end in the child welfare system is found through an examination of the **Child and Family Service Plan Review Final Reports**. All the final reports are available online at

<http://www.acf.dhhs.gov/programs/cb/cwrp/staterpt/>.

Strengths: State officials are more conscious of the need for the parent perspective and birth parents themselves to be "at the table." Limitations: Correspondence with these groups indicates varying degrees of success. Even with good faith efforts, the difficulty is locating and supporting parents when meetings are during working hours. These parents are busy, with limited resources, and their priorities are often to cope and survive.

### **Model C.**

**Citizen Review Panels (CRP) Model:** The Federal Child Abuse Prevention and Treatment Act (CAPTA) requires establishment of CRP's in social service districts in all States. Most States have one district. The New York State legislature created 3 CRPs in 1999. The CRP goal is to evaluate the extent to which the state and the social service districts are fulfilling their child protection functions including in specific cases. The CRP's increase oversight and responsibility by "the public." Its members, may include parent advocates, but it is not guaranteed. No parent has been appointed to the CRP yet.

## **II. AT THE LOCAL- CITY OR COUNTY LEVEL**

### **Model A.**

**Citizen Review Panel (CRP) in New York City:** There is one CRP in NYC with subcommittees in each of the 5 boroughs; 13 members are appointed to it by the New York State Governor and State legislature. "Each panel shall be composed of volunteer members who are broadly representative of the community in which panel is established, including members who have expertise in the prevention and treatment of child abuse and neglect. The NY State Office of Children and Family services (the State administrative agency) shall make available resources to support the needs of the CRPs, plus provide access to information and reasonable access to public and private facilities; The establishment of "fatality review teams" for any deaths of children known to the system is mandated.

### **Model B.**

**A Separate Independent Unit: The Office of Advocacy within the New York City Administration of Children's Services (ACS).** This unit

include parent participation and focuses on parents' rights. It consists of three programs:

- **ACS Parent Advisory Workgroup was created in 2000** to involve parents and primary caregivers whose children are served by ACS and its contract agencies, in planning and reform efforts; to improve quality of services; to identify pressing issues; and to work collaboratively to develop policy and practice recommendations.
- **Parent Advocates.** ACS holds a quarterly forum to exchange information; developed a protocol to expand the model of parent advocate (see New York City Council below). They have accomplished several projects including an on-line Parent Handbook, and a Youth Rights Handbook in process.
- **Parent/Youth Liaison Program.** The ACS Commissioner issued an administrative mandate to establish parent and youth liaison positions in all ACS units. Their roles are: to help parents/youth navigate the child welfare system; to develop peer mentoring; to provide information and referral to services and supports; to voice parent/youth concerns; to accompany parents/youth to meetings including case conferences, court hearings, case service review plans, and other procedures.

#### **Model C.**

**Public Advisory Council.** Founded by the NYC ACS Commissioner, it consists of service providers, public representatives, and the parent co-chairs of the ACS Parent Advisory Workgroup. It meets 3-4 times a year. **For the first time, parents are at the table talking directly to the heads of ACS.**

#### **Model D.**

#### **Child Welfare Parent Advocate Advisory Program (2004). Proposed Legislation: New York City, City Council**

This proposed bill is in two parts. First, it requires that parent staff be hired by each non-profit child welfare agency that has a contract with NYC; and second, and it creates a system-wide/Citywide Body.

Part One proposes: “to establish a child welfare parent advocate advisory program that includes the participation of at least **one (paid) parent advocate in each agency**. Such a program shall ensure that parents receive services including, but not limited to, information regarding the operation of the foster care system, the legal rights and responsibilities of parents within such system,

advice on methods for navigating the foster care system and obtaining assistance from the department, and advocacy on behalf of such parents within the department.”

Part Two proposes: “There shall be a **child welfare parent advocate advisory board**. Such board shall review and comment on department policies regarding foster care services and preventive services to families, including, but not limited to, proposed budgets, requests for proposals, changes in the terms of contracts with foster care and preventive service agencies, proposed legislation, training of foster care workers, publications regarding child welfare services and policies and contractor evaluation systems...” **The Child Welfare Organizing Project (CWOP) is leading the grassroots and advocacy effort to gain its passage.**

## NON-GOVERNMENT/VOLUNTARY “BOTTOM UP” CLIENT/PARENT PARTICIPATION MODELS

### I. NATIONAL/FEDERAL LEVEL

#### Model A.

**Family Strengthening Policy Center:** This is a non-profit program sponsored by the National Assembly and funded by the Annie E. Casey Foundation. Its goal is “...to ensure that parents have the necessary opportunities, relationships, networks and supports to raise their children successfully, *which includes involving parents in decision on how their communities meet family needs.*” Methods: An extensive electronic newsletter; publication of best practices, results of research, programs and policy alerts, with links to other websites for information. This Center focuses on low income families, including but going beyond those whose children are in the child welfare system. [www.nassembly.org/fspc](http://www.nassembly.org/fspc).

### II. AT THE STATE LEVEL

#### Model A.

##### **Mixed Public/Private Partnership Model: Parents Anonymous, Inc.-Shared Leadership (California)**

Parents Anonymous, an established NGO, has created the *Shared Leadership in Action Program*. Its goal is to add the voices of parents alongside professionals to shape policies and practice to make a difference in the lives of children and families throughout California. Methods: They established a collaboration between 6 county Child Welfare Services Departments, Parents Anonymous and the Stuart Foundation. This model program includes parent leadership training and technical assistance to child welfare system staff and parents. Successes: They have identified agency representatives and parents to work on implementing parent leadership strategies in these county child welfare systems. The Departments established early evening hours, provided child care, and selected a parent and social work supervisor to co-chair. Parents also have been invited to serve on the State’s Child Welfare System’s stakeholders’ group, and the California Parent Leadership Team, to train parents throughout the State, to be involved with the California Dept. of Social Services, Office of Child Abuse Prevention’s policy and planning activities. [www.parentleadershipnetwork.org](http://www.parentleadershipnetwork.org); [www.parentsanonymous.org](http://www.parentsanonymous.org)

### III. AT THE CITY LEVEL- NEW YORK CITY

#### Model A.

**Grassroots/ “Bottom Up” Child Welfare Organizing Project.** The Child Welfare Organizing Project (CWOP) is an organization with parents and professionals on the staff and board. Founded in 1995, with a small grant to the community organizing center (ECCO) at the Hunter College School of Social Work, the organization has become a visible advocate for parent participation in community-based agencies and in the public sector of NYC (ACS). Its goals are to reform of the New York City public child welfare system through increased, meaningful parent involvement in child welfare practices and policy-making; to increase the voice of parents, and to project their vision for a humane supportive child welfare system that provides resources to parents in need. Methods: CWOP has involved birth parents through outreach and education on rights, created support groups, presents public testimony and does legislative advocacy. It also pioneered the development of an innovative parent leadership curriculum. CWOP’s model is going from the “case to the cause.” It has provided educational forums and support groups to empower individual parents, but its long term goal is to improve the system at the policy level, and to change the culture of agencies to be more “consumer friendly”. Successes: In the last 10 years, CWOP has seen the results of its influence: its parents now participate in NYC ACS’s Parent Advisory Board. It has stimulated the creation of other grassroots groups. It has also influenced agencies to hire parent advocates on their staff with the goal of changing professional agency culture. It led the effort to develop a Parents’ Rights Handbook written for parents by parents. Challenges: It takes time and resources to build the confidence and competence of parent leaders. The language and priorities of professionals and parents are often different. It is difficult to be both advocates against the system and advisors collaborating with the system. Balance is needed in order to be a legitimate stakeholder without being coopted. Private funding must continue to be available since CWOP will not take government funding, except for specific, well defined projects. See: [www.cwop.org](http://www.cwop.org)

#### Model B.

##### **Public-Private Partnership: Highbridge Partnership for Family Supports and Justice (NYC)**

The Highbridge Partnership for Family Supports and Justice is a new, ground-breaking multi-funded, multi-agency collaborative project in the South Bronx neighborhood of NYC. Its goal is ultimately to reduce child maltreatment and foster care placement in the Highbridge neighborhood. Methods: It is a coalition of more than 50 agencies in a low income area with a high rate of children in placement. Its secondary goal is to bring all the public systems to the table that impact on low income families in the area—education, police, child welfare, youth and community development,

together with community based organizations, social service agencies and the informal institutions including churches and faith-based programs. It also has parents and unaffiliated community residents involved. One of the purposes is to better coordinate formal and informal services in the service of families at risk. Among its initiatives is a subcontract with CWOP (see above) to train parent leaders, and to ensure that those parents from the community also serve as members of the collaborative. It is one of many Neighborhood-based Collaboratives working with NYC's Administration for Children's Services. Successes: Better communication and coordination of services; visibility and legitimacy of child welfare issues in the community in a non-stigmatized way.

#### **Model C.**

**Grassroots-Adversarial: People United for Children (PUFC).** PUFC was founded in 1992 to advocate for institutionalized children in group homes, prisons, and their parents. They provide direct advocacy for parents in need, and also have brought lawsuits against NYC ACS for alleged violations of child welfare policy. PUFC has also used social action at times; e.g. demonstrations. [www.peopleunitedforchildren.org](http://www.peopleunitedforchildren.org)

### **IV. AT LOCAL LEVEL- OUTSIDE NEW YORK CITY**

#### **Model A:**

**Agency-based: Hillside Family Agencies (HFA)-Parents As Partners (PAP).** HFA is a non-profit agency in several locations in New York State. The new approach is called ***Shared Vision***. Its Goal is to involve parents at all levels; "Parents as partners woven into the fabric of our agency." HFA changed its language from serving children to "we serve families with children." Methods: HFA has created a paid Parent Advocate position. It has established 36 parent seats in key decision-making areas. All HFA Boards have parent member. They have created an HFA Roundtable that includes 11 parent members, and 11 staff. They have also provided parent advocate skills training. Strengths: HFA provides stipends for parents for sharing their time and expertise; all staff performance evaluations include "parent friendliness" standards; continuous evaluation, assessment, and planning. At the case/group level, HFA offers parent support and information sharing groups. Challenges: to identify and involve available parents. It is also more difficult to build partnerships at the clinical level because of professional resistance.

#### **Model B.**

**Parents founded, parent led organization: Family Ties—Westchester County, NY.** It is affiliated with "Families Together" (a New York State organization), and the Federation of Families, a national movement. Its Goals are: "parents as full partners." It supports education and skills

development for biological families. It is a parent support organization serving families with children facing any issues (social, emotional, behavioral, learning, etc.). They are strongly committed to a "System of Care" philosophy. History: It evolved from one parent's need for support when she felt she had no voice in treatment of her child at a hospital. It became an informal parent coalition, and then transitioned from a mutual support network to a formal independent nonprofit organization in 2003. It has received funding in part by the Federal government grant, administered through Westchester County. Successes: The establishment of seven parent-resource-centers in the county, each with a Leadership Committee. Paid parents have been hired as staff; additional parent support groups are in 9 locations. Other programs include: parent skills and advocacy training; speakers' bureau; relief for parents; telephone support. It is free at point of delivery. Challenges: Limited resources for expansion; a need for new funding when government funding ends. Parents still feel devalued by a professional driven system. The stigma of mental illness and child welfare remains.

## SECTION TWO:

### THE PHYSICALLY AND MENTALLY DISABLED

#### INTRODUCTION

Participation of people with physical and mental disabilities in the establishment of their rights, protections and services is a well developed area in the US. This is evident in both the law, and in agency policies and practices. Advocacy models of participation are not only limited to directly involving the physically and mentally disabled populations, but also include coalitions of families, social service professionals, and other advocates who work on behalf of the clients' interests. It is important to recognize that many different types of disabled people fall under this broad category. Different terminology has been used for labeling them, with dissimilar meanings at different time periods. In reviewing CCP in this area, it is important to note that the literature and the spokespeople for disabled populations don't always agree on the definitions. No one term satisfies all the stakeholders.

The term "patient" usually refers to someone who is medically ill and who is receiving services from the health system (e.g. from a physician, hospital, rehabilitation facility); "mental patient" has been used for someone receiving psychiatric services, usually in an institution. Social workers generally use the term "client," even when the system uses "patient" or "mental patient." In the 1960's, the term "consumer" began to replace the word "patient" in both the medical and psychiatric systems. It implies more choice and autonomy by those receiving services. It has also been used more broadly to include all people who are not providers of care. In that case, "consumer" does not only mean someone who is "sick" or receiving treatment <sup>1d</sup>.

Traditionally, the terms "mental retardation" and "the mentally retarded" were used, respectively, to refer to the condition and the population. Currently the term "developmentally disabled" is used for those who are mentally retarded and a few other illness categories; "mental disorder" is being used instead of mental illness. For those with physical limitations, over the last 100 years or so terminology has shifted from "crippled," to "handicapped," to "disabled," and even now to "differently-abled." These are attempts to lessen stigmatization and to normalize the needs of this population. The term "behavior health" is replacing "mental health" now. Additionally, all these terms (patient, consumer, disability) are also used to describe social movements which have included both those directly affected and their advocates i.e. the "patients' right movement;" the "disability movement;" etc.

In this section, "people with disabilities" will be the term used generically, unless it is important to be more specific, or to use the language the group itself uses. Here, models will include active people with disabilities who themselves are advocates on behalf of their own group, and advocacy models for those people with mental retardation or mental illness who must rely on others such as their parents, family members, guardians, professional providers and advocates, to express their needs and interests. More and more, the trend is to support the

direct involvement of the consumer.

## **HISTORICAL BACKGROUND**

Historically, services for people with disabilities were a local and state matter, if they existed at all. The Federal government ignored these populations until the 1960's. This was probably because they had few advocates, were stigmatized groups, and were under the control of physicians and other professionals who were assumed to make decisions "in the patients' best interest." There is no history of "top down" approaches at the national level.

There is however, a significant history of "bottom up" parent involvement in the development of rights and services for their mentally retarded children outside government, beginning in the 1950's. This has included the establishment of a range of institutional and community-based educational and support services in the non-profit sector. This group of mostly middle class parents at first fought for or developed themselves, a range of separate services along the life span. In later years, many parents fought to integrate these services into "the mainstream."

Persons with mental retardation came "out of the closet," during the 1960's. Two events increased their visibility. First, President Kennedy revealed that he had a mentally retarded sister. That concern translated, for the first time in US history, into a Federal law in 1963 that funded the construction of mental health and mental retardation facilities. That Act was accompanied by additional public funding for community mental health centers, usually going to non-profit hospitals or newly created independent non-profit health and mental health facilities. Those and many other programs created in the 1960's were designed to increase access to services by the poor and other disadvantaged populations. Liberal government policy mandated "top down" participation of consumers in the planning, implementation, and evaluation of services designed to serve them (see the section on the history of "citizens-at-large").

Second, during the 1960's there were major exposes of the horrendous conditions in State-run facilities that housed the mentally retarded and the mentally ill. One famous case was related to the Willowbrook hospital for the mentally retarded in New York City<sup>7d</sup>. As a result of "bottom up" parent and professional advocacy outside the system, and civil lawsuits brought on behalf of the patients in those facilities, New York State was forced to "deinstitutionalize" and establish a continuum of services outside the hospital. With somewhat less visibility, advocates for the mentally ill and a few courageous former patients in psychiatric facilities (some of whom called themselves "survivors"), fought against "involuntary commitment" - meaning hospitalization against their will. Different groups of the mentally ill also fought for either or both "the right to refuse treatment" and "the right to treatment" in mental hospitals<sup>13d</sup>. Several famous State court cases resulted in a more therapeutic and participatory model of programming inside and outside mental institutions.

By the mid-1970's, with a vocal and visible "bottom up" health rights

movement outside of government, virtually every state had created a “Patients’ Bill of Rights” covering patients in every type of hospital (medical and psychiatric), residential treatment, and nursing home facility (see also section on Senior Citizens). This often included required “top down” “consumer councils,” or “advisory boards,” as well as independently funded programs of “protection and advocacy” for patients who remained in full time care.

During this same time period, the Federal government also passed a law in 1968, strengthened in 1974, that created health planning agencies (known as HSA’s- health systems agencies). For the first time, the government required health providers and consumers to participate together in planning for the health needs of their communities, including giving them a say in which health facilities were built in their areas <sup>3a</sup>. A parallel process was happening in Canada <sup>7d; 13d</sup>, and Australia <sup>9d</sup>. The Federal government however, declined to pass a national patients’ bill of rights in the 1970’s. Currently, there is still a debate in Congress about a proposed Federal bill of rights for patients covered by certain health plans known as “managed care.”

Additionally, during the 1970’s, parents and people with physical disabilities began to collectively organize at the “bottom up” grassroots level. They visibly advocated for access to a range of services, as well as rights and protections, beyond the health and mental health system. The goal was inclusion in all aspects of society as a human and civil right. They advocated for services in the public sector e.g. early intervention programs for children 0-3 years, and special education in schools, which they won in the 1970’s. In 1973, the Federal government passed the Rehabilitation Act which prohibited the discrimination against people with disabilities, and in 1975, passed the Developmental Disabilities Assistance and Bill of Rights Act, which mandated every State to establish “top down” Developmental Disabilities Planning Councils, and Boards of Visitors for residential care facilities to oversee the care given. That same year, Congress also enacted into law, the Education of All Handicapped Children Act, guaranteeing a right to a free public education for every child.

Among the most active group outside government to emerge at this time was the National Alliance for the Mentally Ill (NAMI). Momentum continued during the 1980’s for additional laws and funding for community participation in public health planning, for expansion of rights for people with disabilities, and for new Federal involvement in the newly emerging epidemic of AIDS. Because of “bottom up” grassroots organizing among HIV patients and activists, all legislation mandates “top down” participation of people with AIDS in all facets of planning, prevention, treatment and research. Major pieces of legislation were passed that continue to exist today, including the comprehensive Americans with Disabilities Act (ADA) of 1990 <sup>4d; 5d; 14d; 17d</sup>.

In spite of resistance to expanding rights, opportunities, protection and participation in the Reagan-Bush years, all these laws continued to be implemented and enforced at state and local levels because of a combination of grassroots “bottom up” activism, and creative “top down” models at the administrative levels of government <sup>2d; 5d; 10d; 11d; 12d</sup>.

## CURRENT TRENDS

In recent years, the “self advocacy movement” begun in the 1970s, has blossomed with the mentally retarded and the mentally ill becoming their own spokespersons <sup>12d</sup>. People with physical disabilities have a strong advocacy movement that changed the focus from the concept of “charity” to the concept of “rights” and self-definition <sup>5d</sup>. There have been attempts to form coalitions among all these groups to build a stronger voice politically “bottom up,” and to be visible at the policy tables on the inside.

The challenges to these highly developed and mandated sets of rights to protection and participation are coming from a conservative Federal administration with right-wing elements. First articulated by President Reagan, their ideology challenged the very notion of entitlements. This has included restricting the definition of who is “disabled,” and who is eligible for benefits and services. This is also an era of privatization and “downsizing” (cutbacks). This trend affects all services to disadvantaged populations in the US including people with disabilities who had been viewed as “deserving,” and therefore protected in the past.

## GOVERNMENT-INITIATED “TOP DOWN” PARTICIPATION MODELS OF PEOPLE WITH DISABILITIES

### I. AT THE FEDERAL LEVEL

#### Model A.

**State Developmental Disabilities Planning Councils (DDPC).** Based on a Federal law, every State must create a DDPC; one-third of members must be consumers, defined as disabled people or their parents. They must review regulations, and help draft the State’s annual plan for services. Recently the Developmental Disability Act added a **pilot demonstration program—“Self Determination”** and created the National Center on Self Determination. Consumers will have control over where the money is spent for their care, based on a concept of a “circle of care.” This is a new model to be watched as it is implemented.

#### Model B.

**State Mental Health Planning Councils (MHPC)** Federal government requires States to establish MHPCs as part of the Mental Health Planning Act; and the Protection and Advocacy Act for the Mentally Ill. It mandates both consumer and family involvement. State MHPCs review and provide recommendations to the States on how they spend the Federal mental health funding. The Councils “monitor, review, and evaluate, not less than once a year, the allocation and adequacy of mental health services...” It permits the MHPCs to make site visits to programs; conduct consumer satisfaction surveys; develop public education programs; and handle confrontations with state and local administrators.  
Strengths: MHPC’s serve as advocates for more program resources to reflect

priorities and concerns of the community for mental health services, and as advocates in the community to demystify and destigmatize mental illness.

## II. AT THE STATE LEVEL

### Model A.

#### Community Service Boards (CSB)- New York State.

Based on NYS Mental Hygiene Law, it requires that that each locality establish a CSB. "(Its)...members shall represent the community interest in all the problems of the mentally disabled and shall include representatives from community agencies for the mentally ill, the mentally retarded and developmentally disabled, and those suffering form alcoholism and substance abuse. The CSB shall have separate sub-committees... Each separate subcommittee shall be composed of persons who have demonstrated an interest in the field of service for the particular class of mentally disabled, and shall *include former patients, parents or relatives of such mentally disabled persons* and community agencies... Each subcommittee for mental health shall include *at least two members who are or were consumers of mental health services, and two members who are parents or relatives of persons with mental illness*. Each separate subcommittee shall advise the CSB and the Director of Community Services about the exercise of all policy-making functions that such a board of directors has; and annually evaluate the local services plan."

### Model B.

#### Mixed Mutual Aid and Advocacy: Examples from 3 States:

Parent to Parent (New York State); Parents Helping Parents (San Jose, California); People First (Illinois). These are funded in part by State grants to non-profit organizations. Each of these organizations has chapters of parents in different localities in their state. **Case Example: People First.** 1) It was successful in getting the "Persons With Disabilities on State and Agency Boards Act" passed by Illinois State legislature. That law requires persons with disabilities or family members be included in the membership of any advisory boards or committees on disabilities, human rights, and guardianship and advocacy agencies that receive state funding. 2) It matches parents with other parents for emotional support, and resource sharing. 3) It provides parents with formal training to negotiate system to find services for their mentally ill or disabled children and others.

### Model C.

Family Networks and Consumer Networks. Federal Grants were awarded in 2004 to several States (19 received Consumer Grants; 43 received Family Grants). These Statewide Consumer Network programs are focused on adults with severe mental illness; the Statewide Family Network programs are focused on families of children and adolescents with serious emotional disturbances. *"When users of mental health services and families of children who need services are involved and consulted in their care, services are more appropriate*

*to their needs.*” (Quote from Secretary of the Department of Health and Human Services). *“Providing people who use mental health services a voice will empower them to help create a mental health system that is based on an individual’s needs...”* (Quote from the head Government Agency Administrator).

In New York State, the Consumer Network is titled “The Mental Health Empowerment Project.” The Family Network is titled “Families Together.” Goals: to strengthen policies, programs, and quality assurance in mental health services; to strengthen organizational relationships, and foster leadership.

## **NON-GOVERNMENT/VOLUNTARY SECTOR-INITIATED “BOTTOM UP” PARTICIPATION MODELS**

### **I. AT THE NATIONAL LEVEL**

#### **Model A.**

#### **Grassroots and Advocacy: National Alliance for the Mentally Ill (NAMI) <sup>1d</sup>**

NAMI was founded in 1979 for families of mentally ill people, particularly those suffering from chronic and severe disabling conditions. It is a large and powerful network with State and local chapters around the country. It also has created related organizations: Siblings and Adult Children Networks; Child and Adolescent Networks; and a Multicultural Concerns Network. Goal: to eradicate mental illness and improve quality of life. Their philosophy is that parents are the best (and only) advocates who can provide a day to day reality about their child. The demands of caring for a family member as a result of deinstitutionalization require support and advocacy. Methods. Lobbying and public awareness campaigns e.g Mental Health Awareness Week; advocacy; demand for research in the bio-medical sphere: demand for more funding, and social supports. Successes: moved the Federal government agency, the National Institute of Mental Health (NIMH) into the National Institutes of Health, to reflect the desire for more bio-medical and genetic research on the causes and treatment for mental illness; preserved the Community Support Program of NIMH (during President Reagan’s administration); obtained Federal legislation requiring States to develop comprehensive state plans for services, and required family and consumer participation on State Advisory Councils (see above); and had the category of “psychiatric disabilities” included in the Americans with Disabilities Act. Challenges: Family and patient interests and needs may conflict; NAMI seems less willing to focus on social and family dynamics as contributing to mental illness; professional and family views may conflict.

## II. AT THE STATE LEVEL

### Model A.

**Mixed Public and Voluntary Organization Partnership: The West Virginia Consumer Organization and Networking Technical Assistance Center (CONTAC)**<sup>19d</sup>. This is a partnership between the West Virginia State Office of Behavioral Health Services and two voluntary, non-profit organizations-NAMI-West Virginia, and the Mental Health Association. It was funded in part by a Federal Grant in 1998. It grew out of the West Virginia Leadership Academy for Consumers and Families, a systems/policy advocacy training program begun in 1995. Goals: to end stigma; achieve a mental health system based on the consumer experience and perspective; include consumer input into the decisions of providers; provide a consumer voice; demand that consumers be treated with dignity and humanity; encourage political functioning as a rehabilitative goal. Its philosophy is that personal participation leads to civic participation. There is a need to shift the view of clients from “recipients” to partners, using a self-determination framework. Methods: Intensive training curriculum including internships. The research demonstrates that political participation increased with collective advocacy training. Successes: More than 400 leadership academy graduates in 15 states as of 2003. Consumers are now serving as trainers of other consumers; Consumers are serving on Boards in the government “top down” Mental Health Planning Council, and on other non-profit boards of hospitals and managed care organizations. This model has been replicated in other states in the US. [www.contac.org](http://www.contac.org)

### Model B.

**Grassroots and Self-Advocacy: Self Advocacy Association of New York State (SAANYS)**<sup>12d</sup> SAANYS is part of national movement called “Self-Advocates Becoming Empowered,” founded in 1991 with 150 local chapters. It is modeled after the self-advocacy movement in Scandinavia. Goals: To teach individuals with developmental disabilities to speak out for their beliefs while learning about their rights and responsibilities as citizens; demonstrate the ability of people with disabilities to determine their own destinies. Its philosophy is that gaining greater control over one’s life is linked to influencing one’s environment; this mutual aid model helps decrease sense of powerlessness and alienation among consumers, and links awareness to action Methods: SAANYS Board consists of consumers of service; some professional staff serve in supportive roles. Group members learn to make decisions and choices that affect their lives; Both case and system advocacy programs are implemented. Consumers come together to learn advocacy skills. [www.sanys.org](http://www.sanys.org)

## **SECTION THREE:**

### **SENIOR/ELDERLY PARTICIPATION**

#### **BACKGROUND**

Citizen participation of the elderly has been a well developed area both inside (“top down”) and outside (“bottom up”) government since the 1960’s. Moreover, the voices of seniors in advancing their collective needs and interests are growing on the national/state and local level <sup>1a</sup>. Advocacy models of senior participation not only involve the elderly directly, but also include coalitions of families, social service professionals, and other advocates who work on behalf of senior interests. In examining the history and context for senior participation, it is important to recognize that there are two groups of elderly: the well and active elderly who are prominent advocates on behalf of their own constituency, and the frail elderly who rely on others (family members, well seniors, professionals, advocates) to express their needs and interests. Both groups are considered in this section.

#### **HISTORICAL CONTEXT**

Seniors have been among the most organized groups historically of all vulnerable groups. They have also been among the most effective groups politically in having their voices heard—primarily because they are the highest percentage of voters, and because the US is increasingly becoming a “graying” country. As the Kennedy-Johnson presidential era began in 1960, seniors as a group were disproportionately poor. However, they were articulate and organized

in their fight for benefits and services. Seniors are credited with convincing the US Congress to pass Medicare (the government health insurance program for those over 65 years), in 1965. They also were prominent in promoting a comprehensive package of services that became the Older Americans Act (OAA) that same year, both of which have become institutionalized as government entitlements <sup>5a</sup>.

All models described in this section were developed after the passage of the OAA and Medicare. In addition to creating the Administration on Aging, the OAA authorized grants to States for community planning and services programs, as well as for research, demonstration and training projects in the field of aging. Later amendments to the Older Americans law added grants to establish Area Agencies on Aging (AAA) for local needs identification, planning, and funding of services which included the requirement to establish Interagency Councils on Aging <sup>9a</sup>. These are local mechanisms to bring seniors together with service providers for the planning and coordination of services. Interagency Council have varied in how they have maintained senior leadership over the years.

The OAA also included: nutrition programs in the community as well as meals-on-wheels for those who are homebound; programs which serve Native American elders; services targeted at low-income racial and ethnic minority elders; health promotion and disease prevention activities; in-home services for frail elders, and those services which protect the rights of older persons such as the long term care Ombudsman program <sup>13a</sup>. **The OAA has been the foundation for strong senior participation models in the public (“top down”) sector.**

By the early 1970’s, the movement for the legalization of patients’ rights and protections in health and mental health and disability sectors was also gaining momentum (as discussed in detail in the Section Two). Clearly these developments to legally institutionalize rights and protections in psychiatric and medical facilities, nursing homes and other residential care settings, also affected and involved the aged. This was also the era in which the media exposed extensive patient abuse in nursing homes that led to scandals and exposes. All these related movements occurred at the time, reinforcing the view that seniors needed to both be empowered and safeguarded.

As part of legal regulations, all nursing home providers receiving Federal reimbursement from Medicare or Medicaid, (the public health insurance program for the very low income), were required to implement a comprehensive list of residents’ rights. This included resident protections as well as the requirement that nursing homes establish Resident Councils. Resident Councils are a formal structured self-governing body of nursing home residents which meet regularly to address the problems and concerns of residents. The national 1987 Nursing Home Quality Reform Act further strengthened the mandates for resident councils, and other rights and protections.

Recognizing the frailty and vulnerability of many elderly who reside in long term care facilities, the Federal government also mandated in 1976 “the Ombudsman program.” This required an office to be established in every State or regional Area Agency on Aging. The ombudsman service provides an

independent government-sanctioned guardian for seniors and their family members. It can negotiate problems between a facility and a resident<sup>20a</sup>. Both “top down” Resident Councils and Ombudsmen programs still exist today.

It is not coincidental that various models of senior organizing were occurring outside government in the voluntary (“bottom up”) sector during the decade of the 1960’s. This was the era of civil unrest, civil rights and Presidential leadership with a liberal ideology that believed it was government’s role to eliminate poverty and to meet human needs (This is discussed in more detail in Sections Four and Five, on Low Income/Welfare client and Citizen-at-large participation). One prominent national senior organization, the Gray Panthers, emerged by 1972<sup>13a; 14a</sup>. They modeled themselves in name and approach, after the Black Panthers, a militant organization of young African Americans. The Gray Panthers have attempted to maintain themselves as an intergenerational advocacy organization working together for issues of social and economic justice. They often used social action tactics.

At the same time, other voluntary (“bottom up”) organizations concerned about the frail elderly emerged to ensure the implementation and enforcement of the “inside” models of resident councils and ombudsmen programs, and to establish more advocacy-oriented models that included family councils and paid advocates<sup>18a</sup>. Both the Friends and Relatives of the Institutionalized Aged (FRIA)<sup>12a</sup> and the Coalition for the Institutionalized Aged and Disabled (CIAD)<sup>4a</sup> were founded in the 1970’s “outside” the system in New York City and elsewhere.

## **CURRENT TRENDS**

Over the last few decades, models of collaboration and coordination of services were implemented successfully at the local level through government recognized “top down” Inter-Agency Councils on Aging. Also, “bottom up” and mixed models of senior leadership development, training and advocacy have emerged; e.g. the Joint Public Affairs Committee (JPAC)<sup>8a; 10a</sup> in New York City, and the Senior Action Network in San Francisco<sup>23a</sup>. At the national level, advocacy organizations and coalitions geared more toward national policy advocacy have increased. Major organizations such as the Older Women’s League (founded in 1980)<sup>21a</sup> and the powerful American Association of Retired Persons (AARP), consisting of over 35 million members, have maintained the visibility and viability of seniors in the political process.

On the downside, the emergence of a right-wing, privatization and government benefit reduction agenda could negatively affect major entitlements such as Social Security, Medicare, Medicaid, etc. that have lifted many seniors out of poverty. There are attempts by some politicians to insert a wedge between the older and younger generations. Ageism still exists in the society. There are attempts to divide seniors by age (young-old versus the old-old) and class background (rich versus poor)<sup>24a</sup>. Senior citizens are not a monolithic group, but they will have to remain united and build alliances with other vulnerable groups to defend the gains they have made.

## GOVERNMENT-INITIATED (“TOP DOWN”) SENIOR PARTICIPATION MODELS

### I. AT THE NATIONAL (FEDERAL) LEVEL

#### **Model A.**

**“Ombudsman” Programs** mandated in the **Older Americans Act (OAA) of 1965** as part of Area Agencies on Aging (AAA) <sup>20a</sup>. **Methods:** States are funded by the Federal Government to develop AAAs with Ombudsman programs, but no one model is required. A state may add additional funds to expand it. In many states, external social workers are contracted by the state to be full time advocates. A volunteer ombudsman or paid ombudsman is usually assigned to every nursing home and other residential care facility. Ombudsmen are considered as neutral parties with roles including educators, advocates, and mediators for rights of residents. It is generally recognized that the social worker inside the system may be limited in reporting problems as a result of competing agency priorities. The Ombudsman is not viewed as an adversarial model. The goal is to preserve good provider relations, whenever possible. **Strengths:** They are legitimate system players with an ability to investigate, obtain information, and report to authorities. **Challenges:** to consistently reconcile tensions between being viewed as a patient advocate while building alliances with the inside agency social worker and other staff. The model has worked best on a case advocacy rather than a class/systems advocacy level.

#### **Model B.**

**Resident Councils in Nursing Homes.** Mandated as part of OAA and Medicare and strengthened in The Nursing Home Quality Reform Act, federal law requires that all homes have residents’ councils which are self-governing. **Methods:** It is a group of residents, run by residents, with staff provided by the facility. It meets periodically to address problems and concerns of residents. The focus is on clarification of rights, information seeking and advocacy for resident issues. Councils can invite the ombudsman to meetings. **Strengths:** It provides a space for a collective voice to raise common issues. **Challenges:** Limited autonomy of the resident council; dependence on staff; frailty of elderly; the lack of consistent participation; fear of intimidation.

### II. AT THE STATE LEVEL

#### **Model A.**

**Leadership and Advocacy: Oklahoma Aging Advocacy Leadership Academy (OAALA)** The Aging Services Division of Oklahoma Department of Human Services has established an academy that develops cohorts of volunteers who will advocate for aging programs and services <sup>2a</sup>. It began in 1997 with a grant from the Oklahoma Developmental Disabilities Council. **Methods:** A 10-weekend

training program that identifies and trains staff and volunteers of **all** adult age groups, to serve as advocates for aging in locations and programs of their choosing. Curriculum includes: volunteer skills training and age-related content; lobbying and public testimony. Strengths: Increased visibility and programs. Challenges: Participants are not required to work solely on aging issues. The Academy does not require students to initiate an activity.

### **Model B.**

**Mixed (“Top Down/Bottom Up”)- Planning and Advocacy**: In Illinois, the Department of Health and a university developed and implemented a **consensus model for community health planning** between healthcare providers and elderly consumers <sup>9a</sup> It was an innovative group structure and process for integrating healthcare providers and elderly consumers in community health planning.

Methods: A consensus model, rather than a conflict model was more effective. The group worked best when it was established with the community in control, and with equally shared leadership roles in the group. They required specific criteria for elderly members that included involvement with a health care worker, and understanding of, interest and involvement in community. Conditions for success: 1) accommodate to the characteristics of the community; 2) one formal agency is needed to provide on-going staff time to the collaborative effort; 3) individual outreach is needed for community education. Challenges: Special attention must be paid to elderly participants’ needs, i.e. meeting time, location and mobility. Professional staff from outside the community makes it more difficult to respond to community needs. A lack of consistency of agency and client participants hampered effectiveness.

## **III. AT THE LOCAL OR COUNTY LEVEL**

### **Model A.**

**Ombudsman Office in New York City.** It is located in the NYC Department for the Aged. Besides a professional staff, a large pool of volunteer ombudsmen is recruited due to the many resident homes that need monitoring. Methods: Volunteers are provided with 35 hours of training. They visit a resident home no less than once every ten days. They provide in-service trainings to nursing homes, when requested. They hold community education forums with a variety of senior and other civic organizations. They can attend and support resident councils if they are invited by the council. They address residents’ complaints and make attempts to come to a solution with resident staff. Challenges: No authority to compel changes; not all Residents Councils are effective allies; labor-intensive process of recruiting and retaining volunteers.

## **NON-GOVERNMENT/VOLUNTARY INITIATED (“BOTTOM UP”) PARTICIPATION MODELS**

### **I. AT NATIONAL/FEDERAL LEVEL**

### **Model A.**

#### **Coalition: National Citizen's Coalition for Nursing Home Reform (NCCNHR).**

It developed in 1975, at a national nursing home industry conference by a group of advocates working for then consumer advocate Ralph Nader, and for the National Gray Panthers. Its goal is to improve care and life for residents of nursing homes and other long term care facilities. It was formed because of public concern about substandard care in nursing homes. Methods: NCCNHR provides information and leadership on federal and state regulatory and legislative policy development and strategies It produces publications available for consumers and professionals on long-term care issues. These include resident rights, laws and regulations on such things as physical and chemical restraints, malnutrition and dehydration, and resident assessment and care planning. Publications include a newsletter, policy news, a Technical Assistance Series, Policy Updates and e-mails related to the most common issues facing advocates, families, caregivers and policy analysts. Structure: Membership includes 200 organizations and 1,000 individual members. It is run by a 20-member board, which includes residents of nursing homes. Strengths: Maintaining strong nursing home regulatory language and enforcement. Challenges: To maintain resident membership; conflicts between professional and consumer priorities and strategies. ([www.nccnhr.org](http://www.nccnhr.org))

### **Models B.**

**Grassroots: Gray Panthers.** In 1973, it was formed, modeled in spirit on the Black Panthers, using social action tactics. That year eleven chapters of the Gray Panthers were opened. It currently has 80,000 members. Strengths: It is organized into a loose affiliation of chapters; volunteer and senior driven. Challenges: Lack of staff resources, and lack of centralized focus. [www.geocities.com/graypanthersny](http://www.geocities.com/graypanthersny)

## **II. AT STATE LEVEL**

### **Model A.**

**Family Councils- In different States and Localities.** They have been instrumental in promoting and attaining new legislation, such as prohibiting nursing homes from interfering with family councils and requiring facilities to support councils in several new ways. Goals: to require facilities to: 1) make bulletin board space available; 2) notify relatives of newly admitted residents about the family council; 3) mail meeting and contact information, at least quarterly; 4) designate a specific staff person to respond in writing, within a fixed time frame, to council requests and concerns. Methods: Structures vary, but usually tied to a non-profit Community Based Organization (CBO). Strengths: Family member or relative leads effort. Effectiveness is based on strength of council, support from outside advocates and inside leadership of professional staff. Challenges: Turn over among family leaders, usually tied to the length of stay of their resident member.

### **Model B.**

#### **Coalition and Advocacy Organization: Long Term Care Community Coalition(LTCCC) in New York State**

An advocacy organization made up of senior and health activists and organizations which monitor nursing homes and other long term care agencies, and whose role is to represent the “consumers” of services. Goals: to serve as a watchdog on state-wide policies and nursing home practice, and to advocate on Federal policy issues that affect NY State facilities. Methods: They develop indicators and issue “Report Cards” on how well the legislative and administrative branches of New York State government do in protecting the resident community. They lobby for bills such as “safe staffing,” improving the ratio of nursing staff to residents; and affordable drugs for seniors. They publicize the “State Enforcement Actions Against Nursing Homes” which is an official government report on facility abuses and the fines issued to them. Successes: The passage of an Assisted Living Reform Act, which provides protection for people in assisted living. They take credit for a Patient Protection Section being established within the Attorney General’s office (the State’s highest elected law enforcement officer). Among their publications is a resource guide for assisted living for consumers and staff; a newsletter, the *LTC Monitor*, and a bill to require living wills and health care proxies. [www.ltccc.org](http://www.ltccc.org)

## **IV. AT THE LOCAL OR COUNTY LEVEL**

### **Model A.**

#### **Senior Leadership and Advocacy: Joint Public Affairs Committee for Older Adults (JPAC) in New York City.**

JPAC was founded in 1977, by the Jewish Association for Services for the Aged (JASA). JPAC is an grassroots senior advocacy group that has evolved into a multicultural, interdenominational social action coalition of older adult representatives from more than 200 senior centers and community groups. Its goals are to give older adults a voice in community policy-making processes that affect their lives; to protect, improve and expand services, programs and benefits for older adults and their families. Methods: Established an Advisory Committee composed of older adult representatives with six sub-committees from various NYC groups and organizations; it provides information on issues within the older adult community in collaboration with senior organizations throughout the city; organizes public rallies, crime prevention programs, letter writing campaigns, and meetings with elected State and local officials. Among their publications to support collaboration and advocacy is a *Toolkit for Advocacy*.

The ***Institute for Senior Action (ISA)*** is JPAC’s largest training component founded in 1994. It provides older adults with the tools and training to advocate on their own behalf on legislative and community issues. The 10 week training institute integrates critical aging policies with grass roots social action. Curriculum: education on: city, state & federal budget legislation processes, voter registration/ outreach, senior policies, programs & entitlements, organizing across generations, fundraising, volunteerism, visits to legislator’s office, conflict

resolution and public speaking. Participants who complete the training are provided with on-going staff assistance and timely updates on policies.

Strengths: major legislative and community victories claimed: \$162 million dollars of new funds for aging services and partial restoration of SSI; the creation of the New York State Patient's Bill of Rights, legislation that provides prescription drug coverage to low income seniors, and the establishment of a specific committee within the NYC City Council to deal with the concerns of the aging. Seventy-five percent of seniors who graduate from ISA have taken a leadership role within their organization. Challenges: Activities become ends in themselves for seniors; Sustaining and supporting continued involvement; agenda may be controlled by professional staff.

### **Model B.**

**Coalition: The Coalition of Institutionalized Aged & Disabled (CIAD).** CIAD is a coalition of nursing home and adult home resident councils. (Adult Homes are private community residences funded by government that house many mentally ill and low income adults.) In 1973, a group of resident councils began meeting to organize a unified voice for the institutionalized elderly and disabled. In 1980, CIAD became a non-profit organization, with a hired executive director, community organizers, and large core of volunteer resident leadership. Goals: to help individual resident councils develop into effective groups in each facility; to work on Federal, State and local regulatory issues that affect residents' quality of life. Methods: It uses a coalition model as the vehicle to enforce and strengthen the rights of adult home and nursing home residents. CIAD facilitates leadership trainings and on-site visits with resident councils. Session topics include: organizational tools (e.g. by-laws), council structure, leadership development, meeting skills, committee development, increasing residents' participation; resident rights, and problem-solving methods. CIAD also responds to individual complaints and provides information and referral services to residents, family member, the media and the general public. Successes: CAID participated in media expose about terrible conditions of adult homes and the lack oversight from state inspectors. It has maintained dozens of thriving and effective Councils. Challenges: Difficult to organize the frail elderly; the City government is slow to make policy change; low resident morale; opposition and resistance to change by the private facilities.

### **Model C.**

**Grassroots and Advocacy by Family Members: Friends and Relatives of the Institutionalized Aged (FRIA).** In 1975, FRIA, founded by social work advocates, began organizing family groups at several homes. In 1976, FRIA was established as a not-for-profit organization with legal and social work staff. The board is a mix of professionals and family members. Goals: to inform consumers (usually relatives of current or would-be nursing home residents) to make better decisions about eldercare for their own family members; to insure that nursing home residents receive prompt, high quality and compassionate care. Methods: 1) Family and Friends Councils in each nursing home: support nursing home family organizations established at the facility; recruit and train family leaders; provide

workshops for family members and professionals. 2) Consumer Education: develop educational materials including a *Guide to Choosing Home*; convene leaders' coalition meetings for Family & Friends Council; 3) Telephone Hotline to field questions about: long-term care options and financing, nursing home evaluation, selection and admission referrals; train volunteers in advocacy skills; 4) Intervention with facilities by the NYC and NYS Department of Health: monitor nursing home inspections process and reports; 5) Public Policy Advocacy: testify on legislation, regulations, public agency and provider practices and standards; connect nursing home residents and relatives with the media, government agencies, and academic researchers [www.fria.org](http://www.fria.org)

#### **Model D.**

#### **Advocacy Coalition: Council of Senior Centers and Services of New York City (CSCS).**

CSCS is a network model that represents 265 senior service organizations, founded in 1978. Goals: to address the challenges and opportunities facing seniors and their families, and the nonprofit organizations serving them. Methods: 1) Training and technical assistance programs to help CSCS organizational members improve and maintain their fiscal, management and technological infrastructure; 2) Publications for members; 3) facilitate exchange of ideas among CSCS members, and between them and government, business, and local communities; 4) lobbying for elderly legislative agendas at City and State level, i.e. Senior Citizen Rent Increase Exemption program that enables seniors to remain in affordable housing; 5) surveys of all senior centers, to research common strengths and challenges in current programs provided for the elderly. Successes: A coalition of agencies has resulted in greater unity and a united platform; it has achieved visibility and legitimacy among public and its CBO constituency. Challenges: Relationship with government policy makers and state government administrative leadership is conflictual; government officials often view CSCS as oppositional to *their* agenda for the elderly; CSCS agency priorities may conflict with the seniors' agenda; seen as advocating for services rather than advocating for seniors. [www.cscs-ny.org](http://www.cscs-ny.org)

## **SECTION FOUR: WELFARE-LOW INCOME CLIENT PARTICIPATION**

### **HISTORICAL CONTEXT**

In the US, welfare and low income clients are the population group with the least government sanctioned, “top down” participation models at any level. It is also the group that has had only interim success organizing clients and building a lasting grassroots, “bottom up” movement for recognition and rights from the government. Four reasons are usually given for this: first, in a work-oriented, individualistic, capitalistic society, all “able-bodied” adults are presumed to be working; thus, welfare clients are a stigmatized group of mostly women who are viewed as dependent and “undeserving.” Second, there is a strong ideology supporting the “American dream.” This means that anyone who works hard enough can join the “middle class.” This belief leads most Americans to define themselves as middle class, regardless of their circumstances. Unlike in Europe with its strong labor and union base, there has been little effective organizing around a “class” or a US economic agenda; nobody wants to be seen as poor given the stigma.

A third reason that keeps people in the US from organizing around class issues relates to racism— the permanent black-white divide that continues to separate groups racially in spite of common economic interests. A fourth reason is the division between the “welfare” and “working” poor. Given the strict regulations on who can receive benefits, and the low wages paid to many workers who are not unionized in the US, there are millions of working Americans who fall just above the official poverty line. This group struggles to make ends meet on a minimum income, and are neither eligible for medical insurance nor public assistance. Thus, resentment is created in the latter group that has prevented these two populations from joining forces.

Nevertheless, in times of economic crisis, the government has been forced to step in to help needy citizens. Since the mid-1930’s, the Federal government in partnership with the States has provided minimum income support to children with a single parent (almost always, a mother). Originally called Aid to Dependent Children (ADC), this program was changed in 1962 during the era of the liberal President Kennedy, to Aid to Families with Dependent Children (AFDC). The name change reflected a policy shift; the unit of support was indeed the family. AFDC allowed two parent families with an unemployed husband to remain together and still receive benefits.

The 1960’s was the time when Presidents Kennedy and Johnson focused government attention on issues of poverty and race; indeed, President Johnson declared a “war on poverty and racism.” The civil rights movement, social unrest and urban riots resulted in the creation of major “top down” social legislation that was designed to eliminate poverty—and one of its goals was participation by the

disenfranchised and poor in civic life as well as their inclusion in the “American Dream.”

Interestingly, the dozens of laws creating well-funded anti-poverty programs focused on services to low income neighborhoods in urban and rural localities. Funding did not go directly to the people and their pocketbooks; instead it went to new and established CBO's. The solutions to end poverty were political and social solutions, not economic ones; that is, its goals were to provide “equality of opportunity” rather than provide direct income support. Liberals believed that poverty would end if poor people had access to decent early childhood and public school education, housing, health care, job training, and legal assistance. So there were major funded Federal initiatives in every one of those areas. There was also a strong mandate that poor people had to be given opportunity to gain a collective voice; therefore, for the first time Federal funds were available for local community organizing (known as “community action programs”-CAPs). The government enforced a “top down” mandate for “maximum participation of the poor” built into almost every social and economic program enacted into law. One of the most comprehensive regulations for low income parent participation is found in the Head Start (pre-school) program. It was one of the “stars” of the government anti-poverty program in terms of funding and enforcement (see model below). These required structures for parent/client participation, together with laws to end discrimination and promote inclusion, were all part of the government's solutions to end poverty and racism.

The institutionalized “top down” strategies to end poverty occurred at the same time that “bottom up” national grassroots movements to end racism and poverty emerged among Black Americans with a great deal of support from White allies. It is beyond the scope of this policy paper to discuss these movements, except to note that they appeared to visibly and overwhelmingly Black and focused more on race than class. Although the majority of poor people in the US were White, Blacks took the lead; and given the stigma about poverty and welfare discussed above, there was not the same kind of mobilization of the White poor and “working class” in the country. For example, after the assassination of Dr. Martin Luther King in 1968, a major “poor people's campaign” was organized by his followers with thousands of people camping out for weeks in front of the White House and the National Capitol. Although attempts were made to include other groups, it was disproportionately Black and portrayed in the media as such.

There was one “bottom up” movement then that did attempt to directly organize “welfare recipients” in the late 1960's<sup>3w; 6w</sup>. Its intent was to change the structure and increase financial benefits of public welfare (AFDC) and make it a full Federal entitlement. Again it tried to bring poor Blacks and Whites together, but its leadership was predominantly Black. Ironically, there was a positive response from President Nixon who followed President Johnson in office in 1969. He proposed new laws for income-support. Looking back, President Nixon appears to be a liberal rather than a conservative Republican president in terms of the social and economic programs he supported then. Among the legislation he proposed was a Federal takeover of all the separate “welfare” programs which

included AFDC. This meant that States would no longer have to contribute a share of the funds, and that financial benefits would be standardized and guaranteed for all Americans. Social workers were very active participants in this welfare rights movement, as well as in all the social and economic justice struggles of the 1960's.

Nevertheless, there were strains and conflicts within these "bottom up" movements for welfare reform that no doubt gave comfort to those who opposed them in Congress. And of course, the other problems of President Nixon ("Watergate;" the Vietnam War) resulted in his resignation. This dampened the momentum for "bottom up" mobilization of low income people. As a result, two new Federal Social Security benefits were created for all welfare categories *except* the poor, that is, *without* the inclusion of the AFDC program.

Overall, the Federal "anti-poverty" programs of the 1960's and early 1970's did for a time, reduce economic and racial gaps between Blacks and Whites, and rich and poor. However, the economic recession and inflation in the 1970's diverted attention away from organized social activism outside, and liberal forces inside, government. Ever since, there has been a minimization of the problem and persistence of poverty by most political leaders. What has emerged instead is a strong tendency to "blame the victims," the poor themselves. Conservative Congressional leaders began to focus on "welfare cheats" culminating in President Reagan condemning people who were "on the dole," and demonizing women on welfare as "welfare queens." Work requirements were legislated into the AFDC law, and eligibility continued to tighten throughout the 1970's and 1980's.

## CURRENT TRENDS

With continuing ambivalence of the public and increasing condemnation by policy-makers, AFDC remained intact until the mid-1990's; in fact, the numbers of people receiving public assistance increased across the country. A move from "blaming the poor" to "punishing the poor" came to the forefront of the public policy agenda as a result of the 1994 election of a conservative Congress. A record number of declared "right wing" representatives took control of the House of Representatives. Ironically however, it was President Clinton who came into office in 1992 who promoted welfare reforms that were going to "end welfare as we know it." By 1996 in the midst of a heated second term Presidential election campaign, Congress repealed AFDC and passed (and President Clinton signed) the Personal Responsibility and Work Opportunity Act better known as TANF (Temporary Aid to Needy Families) <sup>1w</sup>. **Nowhere in this legislation is there recognition that welfare recipients are stakeholders who should participate in shaping TANF policies and programs.** Indeed, in TANF, welfare clients have no rights beyond an occasionally used "right to a fair hearing" process when benefits are denied. On the contrary, there are lots of restrictions and sanctions on welfare clients if they don't comply with the work and other requirements.

Today, there are many "bottom up" coalitions of professional advocates including the National Association of Social Workers, and small grassroots

organizations of low income people who oppose “welfare repeal.” While these groups were not successful in preventing the passage of the TANF law in 1996, they have taken credit for several changes at the state and local levels with respect to lessening its “punitive aspects,” and expanding educational opportunities. These organizing efforts culminated in 2003 in a national march to promote the issue of poverty as a human rights issue. The march was led by the Kensington Welfare Rights Union (KWRU) and other similar groups<sup>2w; 6w</sup>. There was also a national march for immigrant rights in the fall of 2003 that brought together diverse grassroots, advocacy, and union groups around the issue of the right to work and the right to government benefits.

There continues to be a determined group of grassroots leaders and professional supporters who are keeping the issues of poverty and social and economic justice alive. Many of these “bottom up” efforts are funded by foundations, membership dues, and donations. Recently a web-based networking project has been created that identifies hundreds of groups working on issues that affect and involve low income people across the country (the Low Income Networking and Communications Project-LINC).

## **GOVERNMENT-INITIATED (“TOP DOWN”) WELFARE/ LOW INCOME CLIENT PARTICIPATION MODELS**

### **I. AT THE FEDERAL LEVEL:**

#### **Model A.**

#### **Inclusionary Structures: Participation of Low Income Parents of Children in Head Start Programs.**

As part of a Federal law since 1965, the regulations for mandated parent participation have expanded to make it one of the most comprehensive models of parent participation in all aspects of this early childhood developmental program. It is one of the few programs that have been evaluated and pronounced as effective for parents:

- 1) At the Program level: Parents are involved in policy-making and operations across all areas of Head Start: Child Development, Education, Health, Nutrition, Mental Health, Community Advocacy; etc. It provides opportunities for parent training, skills, planning classroom curriculum, and enrichment activities. Parents serve on educational committees and policy groups, including health services and other committees.
- 2) At the community level: There are mandated roles for parents and others related to community partnerships that include parents in educational reform and community schooling.
- 3) There is a National organization of Head Start Parent Boards that attempts to influence Federal policy. Strengths: expands parental strengths and interests; increases ability of parents and staff to collaborate in child’s growth and learning; develops self-esteem; builds parent skills while helping to organize and enhance community services and resources that best respond to parents’ needs and interests.

## II. AT THE LOCAL LEVEL

### Model A.

**Citizens Advisory Committee (CAC) of the New York City Human Resources Administration (HRA).** The CAC was created by NYC HRA Commissioner in 2002. HRA is the public agency that administers TANF and other welfare and job related programs. The CAC is the result of various “executive orders” issued by HRA Commissioners that date back to 1975. Goals: To advise on policy development, program planning and program evaluation with respect to public assistance, medical assistance and services; and also to advise the Commissioner on planning regarding the reauthorization by Congress of Federal welfare laws. Structure: The committee meets quarterly and has about 35-45 members, most of whom are Executive Directors from large non-profits in NYC. About 5-6 “consumers” also hold seats including half who come from a “bottom up” advocacy organization-Community Voices Heard (see below), and 2-3 “unaffiliated” consumers. Advisory board members form various committees around the topic of *prevention*- keeping people off welfare, and *retention*- helping people get jobs and maintain them. Strengths: Provides clients and the public with information on HRA policies and procedures; clients serve as advocates and spokespeople; allows for representation of real experiences of welfare recipients. Challenges: Inability to share HRA committee information in community meetings; difficulty in obtaining copies of workgroup results; perceptions of client members as a “rubber stamp” for HRA.

## NON-GOVERNMENT/VOLUNTARY INITIATED (“BOTTOM UP”) CLIENT PARTICIPATION MODELS

### I. AT THE NATIONAL LEVEL

#### Model A.

##### **Policy Advocacy and Legal Rights: Welfare Law Center**

Founded in 1965, the Welfare Law Center has worked with and on behalf of low-income people to ensure that adequate income support is available to meet basic needs and foster healthy human and family development. Goal: Promote the creation, maintenance, strengthening, and fair administration of income-support programs, and, as appropriate, to address other publicly supported means of improving low-income people's income. Methods: 1) Legal representation and policy advocacy around the country to improve the administration of cash assistance, Medicaid (public health insurance for the poor), Food Stamps, and Child Care; 2) Direct participation in significant litigation around the country; 3) Communication with a national network of legal and policy advocates; coalition building; 4) training; and public and media education; 5) A periodic newsletter on welfare reform issues, media contacts, and web pages for information on welfare legal developments and community organizing; 6) Special new project the web-based Low Income Networking and

Communications (LINC) to provide technical assistance and communication possibilities to these “bottom up” groups.

[www.lincproject.org](http://www.lincproject.org); [www.welfarelaw.org](http://www.welfarelaw.org)

## II. AT THE STATE LEVEL

### Model A.

#### Grassroots and Advocacy: Kensington Welfare Rights Union (KWRU).

It was founded by a group of poor women in April 1991 in response to Pennsylvania Governor’s welfare cuts. KWRU is a multi-racial organization of, by and for poor and homeless people that works on all three levels—national, state and local. Goal: to organize welfare recipients, the homeless, the working poor and all people concerned with economic justice; to make poverty in the US declared a violation of human rights by the UN. Methods: 40+ member organizations are available to speak about the campaign-- human rights, poverty, the changing economy, and organizing. KWRU has led the national organization, the Poor People’s Economic Human Rights Campaign. It sets up tent cities when shelter system is full. It is supported by university professors and other professional advocates. Successes: Established "Human Rights Houses" as bases for emergency housing, free food and clothing distribution, and free medical clinics; assisted over 500 families in obtaining housing and utilities; increased media coverage of poor people; built coalition out of many different needs. Challenges: Lack of resources; stigma of clients; inability to mobilize large groups of welfare clients. <http://www.kwru.org/index.html>

## III. AT THE LOCAL LEVEL

### Model A.

#### Coalition of Professional Advocates and Clients: Welfare Reform Network (WRN) in New York City.

It is sponsored by the Federation of Protestant Welfare Agencies, an umbrella organization of 285 agencies. It is a 12-year-old coalition of organizations and individuals that advocates for humane income security policies. Goal: to advocate for a welfare system that assures all people a decent standard of living without stigma. Structure: A Steering Committee plus 12 working committees: Child Care; City Welfare Issues; Client Empowerment; College Task Force; Education & Training; Federal Welfare Issues; Media; Mental Health; Queer Economic Justice Network; State Welfare Issues; Task Force on Substance Use and Public Assistance; and Women, Welfare and Abuse Task Force. Methods: information sharing, grassroots activism, networking, public and consumer education, and legislative and administrative advocacy at the city, state and national levels; newsletter. Strengths: A collective voice for welfare recipients; recognized as a legitimate advocacy player; Challenges: Lack of resources; organizational members preoccupied with more immediate priorities

of individual client advocacy and support; Different priorities and strategies between professionals and clients at times.

### **Model B.**

**Grassroots: Welfare Rights Initiative (WRI).** Founded in 1995 by professors Mimi Abramovitz and Jan Poppendieck at Hunter College, of the City University of New York (CUNY), WRI grew out of the debates over welfare reform: the absent voice of welfare recipients; the negative stereotypes of poor women that dominate decision making; and the failure to envision humane reforms that realistically reflect the needs of welfare recipients. It consists of current and former college students who are receiving or whose families receive welfare benefits: **Goals:** help students to become informed about local, state and federal anti-poverty, social welfare and higher education policies; provide students with the opportunity to participate in organizing and leadership development; and facilitate their interaction with faculty, community advocates, service providers and policy makers. The **philosophy** of WRI is to support and empower CUNY students (particularly those with first-hand experience of poverty), staff, faculty and diverse communities with information about current welfare policy and its impact on access to education and training. **Methods:** 1) Community Leadership Seminar: CUNY students study the history of social welfare policy and become equipped as organizers, trainers and advocates for the college campus and their communities. Students receive academic credit and community organizing internships; 2) Public Education & Training: WRI students conduct classroom presentations on CUNY Campuses; students participate on citywide panels, lead speak-outs, and testify at public hearings. 3) Advocacy Training Mobilization: A joint program with the CUNY Law School that trains law students for advocacy on behalf of students whose education is threatened by having to fulfill extensive work commitments. 4) Campus & Community Organizing: fosters collaboration among leadership seminar participants and community groups linking campus, neighborhood-based, city and statewide welfare advocacy. **Successes:** Won vote to receive student fees; raised \$180,000 in grants from seven foundations; WRI in collaboration with CUNY Law School have assisted more than 1900 students who were at-risk for being forced out of college; won legislative victory to have time in classes count toward welfare work requirement. **Challenges:** Despite WRI's efforts, the number of welfare recipients in colleges in NYS has dropped from 27,000 in 1995 to 5,000 in 2004; continuing stigma.

### **Model C.**

**Grassroots Mobilization and Case Advocacy: Welfare Rights Coalition (WROC) in Seattle, Washington.** WROC is made up of families who receive Temporary Assistance for Needy Families (TANF) and families who have left TANF for low wage jobs. **Goals:** To change the welfare system so that it is more responsive to the needs of low income people and treats public assistance recipients fairly and with dignity; to effect economic and social justice by educating and empowering low-income parents. **Methods:** Organize groups to monitor how welfare and family policy is implemented at their local welfare offices

and at the State legislature; referrals to volunteer legal advocates to assist recipients in fair hearings; assistance in starting and maintaining welfare rights groups; Training on how to talk to legislators concerning welfare issues; leadership development; Workshops to provide current and accurate information on changes in the welfare system including “Know Your Rights;” Skill training in public speaking, working with the media and telling your story from a position of power. Strengths: Individual and collective advocacy; reduced stigma; enforced Legal Rights; improved program administration and greater agency accountability.

#### **Model D.**

##### **Grassroots Membership-Community Voices Heard (CVH) in New York City.**

It was founded in 1996 as a project of the Hunger Action Network of New York State by women on public assistance to impact on the welfare system. Goal: To build power for all low-income people. Structure: CVH is membership-led, directed, and operated by low-income individuals, mostly women, working together to build the power of families, communities and low-income people. Methods: Focuses on multi-issues related to welfare, education, job training, living-wage jobs, housing, and economic development. CVH uses a multi-pronged strategy which includes community organizing, public education, public-policy work, coalition building, leadership development, training low-income people about their rights, political education, and direct-action issue campaigns. Specific focus has included: welfare reform, job creation, worker organizing for a living wage, access to education and training. Leaders also serve on NYC HRA Commissioner’s Advisory Board (see above). Successes: Moved New York City’s Human Resources Administration (HRA) to implement a welfare-to-work program to create 10,000 jobs for people on welfare; convinced the Mayor and HRA to continue the Parks Opportunity Program. As a result 7,000 women facing cut offs from TANF will be hired by NYC Parks Department for a decent wage; influenced New York State to create a \$65 million pilot jobs program, the NYS Wage Subsidy Program, to provide jobs, education and training for people on welfare. Challenges: to maintain advocacy stance and still collaborate with government; funding and resource constraints. <http://www.cvhaction.org>

#### **Model E.**

##### **Grassroots Empowerment: Make the Road By Walking in New York City.**

Founded in the Spring of 1997 in the wake of legislative attack on America’s poor and immigrant communities, Make the Road by Walking initially focused exclusively on organizing with immigrant recipients of welfare. Goal: Promote economic justice and participatory democracy by increasing residents’ power to achieve self-determination through collective action. Methods: 1) Organize for economic justice, workplace justice and a safer and healthier environment, through building and block associations; 2) Special youth organizing and

leadership development for expanded opportunities and support; 3) build and sustain long-term, collaborative relationships with community residents and their families by creating a variety of ways in which to become or to stay involved; 4) Publish reports, such as *System Failure*, *Policy or Pretense*, about abuses in local sweatshops and mismanagement within New York City's welfare bureaucracy; 5) Facilitate weekly meetings to share experiences and strategize collectively on how to ensure that workers' rights at work are respected. Successes: Created The Complaint Campaign against then Mayor Giuliani's discriminatory and dysfunctional welfare bureaucracy; led a coalition of Brooklyn community groups that hosted a community conference on lead poisoning; successful campaign to get New York City's HRA to translate all written materials into nine languages.

<http://www.maketheroad.org/>

## **SECTION FIVE:**

### **CITIZENS-AT-LARGE PARTICIPATION**

#### **OVERVIEW**

There is no single standard or legislation that mandates citizen participation across the public sector. Federal and State level requirements for

citizen participation vary widely, depending on the legislation produced and the level of government which produced it. Generally, when the Federal government requires the 50 States to implement any CCP guidelines, it gives wide latitude to the States on how to implement them. Likewise, when a State originate its own, or implements Federal citizen participation regulations, it usually give localities flexibility in how to structure CCP at the local level.

Hence, there are a wide range of models described here: from traditional **public hearings** to more labor and resource intensive participatory models such as **focus groups, task forces, visioning sessions**, etc. Some examples from Canada, Europe and elsewhere were uncovered and these are identified when they seem relevant for Israel.

The major focus of this section is on “top-down,” inside government roles and responses to CCP policies, although some outside-the-government, “bottom up” models are presented. Additional examples of those CBOs and coalitions influencing government from the outside are found in the specific program categories presented in the previous four sections.

## **HISTORICAL CONTEXT**

There has been a rich history of experiences with citizen participation in community and political life beyond voting for an elected representative government; but there has also been a history of distrust between the government and citizen advocacy groups, and perceived failures of those mechanisms created for inclusion of citizens.

Citizen participation in the US begins with Constitution and First Amendment right of citizens to participate in, and influence government by ensuring the rights of free speech, of peaceful assembly, and the right to petition government to redress complaints. DeTocqueville, a French social critic wrote in the 1800's, that a marvel of America was the willingness and ability of citizens to form myriad voluntary associations<sup>10</sup>. The type of “citizen” allowed to participate civically has been expanded over the centuries since the founding of the Constitution in 1789. Over the centuries, the right to vote was extended to former slaves (African Americans), women, and youth (18-21 years) through the Constitutional amendment process. Debates continue currently in the US about the role that non-citizen residents should play in civic life at the local and neighborhood levels. There are even proposals suggesting that they vote in local elections.

The “modern” timeframe at Federal level for recognized citizen participation is usually acknowledged to be in the 1950's with the Federal Urban Renewal program to improve poor neighborhoods. It accelerated in 1960's when the goals of inclusion and equal opportunity for all citizens were demanded by organized citizens outside government through the “civil rights movement.” At the same time, and to some degree in response to organized protests, President Lyndon Johnson who was ideologically liberal, declared a “war on poverty and racism.” As discussed in the Section four, mandated “top down” community and client participation in the planning, implementation and evaluation of the social programs was created as a part of the liberal philosophy to strengthen

neighborhoods, enfranchise low income and minority citizens, and empower clients from among the disaffected segments of society. This concept of structured and mandated involvement of CCP also extended to the consumer and environmental movements beginning in the 1970's <sup>2; 13; 16; 4</sup> .

By the 1970's, most government mandated citizen participation efforts were institutionalized in legal regulations. With a decade of experience with these mechanisms, concerns emerged in the 1970's and 1980's about their effectiveness. Some critics distinguished the concept of "community development," a "bottom up," outside-the-government approach, from the "top down" client/citizen participation approach, pointing out the limitations or failures of the latter <sup>15; 21</sup> .

One noteworthy government process with implications for this current era, was the establishment by the Federal government of an Advisory Commission on Intergovernmental Relations in the late 1970's. It identified 155 Federal grants to state and local governments from 16 different Federal agencies that mandated some form of citizen participation. The terms for citizens used by the Commission varied; they were referred to as consumers, clients, ethnic and racial minorities, and the general public. The most common form of participation established by most states and localities were **Boards and Committees with advisory functions**, but several of such structures had some decision-making authority. <sup>2</sup> **Public hearings** and "**community consensus**" models of involvement were the next highest types of participation.

Recommendations were made to the government by the Commission that "*governments at all levels provide sufficient authority, responsibility, resources, commitment and leadership for effective citizen participation in their own directly administered activities...*"(p. 307). Yet, it also acknowledged that citizen participation processes could compete with the basic responsibility and authority of elected officials, and could distort the representativeness of such processes. Nevertheless, they urged the President to **authorize a single agency with authority** to ensure consistent application and evaluation of citizen participation structures with funding to provide support, training, technical assistance, research, standards, etc. They also recommended several specific structures to be instituted in every government program. These included open processes such as **surveys, public hearings, community forums**, as well as **permanent Councils, Boards and Commissions** with a majority of citizen members given decision-making powers.

The specific recommendations were never formally adopted; that is, there is still no single agency or uniform standard for CCP. Yet most of the Federal agency structures identified then, remain in place, regardless of the political party in control of Federal, state or local governments. There are differences however, in the level of support and strictness of implementation and enforcement by government, which does seem to depend on the political climate if not the majority party. The current Republican administration has not articulated citizen participation as a priority to influence policy <sup>20</sup> .

## CURRENT TRENDS

In the last decade of the 20<sup>th</sup> century, primarily in the era of President Clinton, additional or alternative terms have emerged to **promote a (pro)active citizenry**: civic engagement <sup>20</sup>; civicness; citizen-driven policy formation <sup>22</sup>; citizens as customers or owners <sup>18</sup>; social citizenship <sup>14</sup>; community-building <sup>12</sup>; social capital <sup>20, 22</sup>; “communitarianism” <sup>22</sup>; and community-owned government <sup>13</sup>. Discussion of these concepts and mechanisms however is beyond the scope of this policy paper.

Also since the 1990’s, there has been an increasing interest in and funding of **community collaborations and partnerships among government, community institutions and social agencies**. These often link economic and social development with social services. Among them is the Federal government program labeled “empowerment zones” created to redevelop socially and economically low income areas, with mandated broad citizen participation. Other “top down” policy mandates of CCP include programs created to coordinate comprehensive community-based systems of care and support, or to solve community problems such as substance abuse and child welfare, or to improve public health. These are usually funded both by national government and national private foundations and invite all the community stakeholders to the table. Many of these mechanisms have explicitly or implicitly identified clients and community residents among the “stakeholders” <sup>13; 31</sup>. The term “**mixed model**” has been used to mean organizations that combine organizing with development and services, like ACORN <sup>25</sup>.

Beyond the models of participation, the literature on citizen participation includes studies of which citizens are likely to participate (by class, type and other characteristics), what motivates people to participate, and what benefits they receive from participation <sup>18; 5</sup>. Research suggests that economic, social, and political participation in the US are unevenly distributed throughout the population <sup>18; 4</sup>. There is less participation and less influence by distressed/“at risk” communities which are usually those areas with high numbers of welfare recipients and low-income clients. This phenomenon is also noted in international community development literature in Canada, Great Britain and elsewhere <sup>17; 29; 32</sup> where under-representation of the lower income population in neighborhood voluntary leadership, has also been identified. Nevertheless, there is evidence of active participation by some residents in poor neighborhoods and the organization of low income groups that could be encouraged by both the public and private sector <sup>28</sup>.

Finally, some attention is paid in the literature to the many **roles and functions of the professional community worker** that include building community capacity, and fostering empowerment practice. These have their roots in community organizing and development of the 1960’s and 1970’s <sup>16; 21; 13</sup>. The literature includes the identification and elaboration of the skills of the professional “community worker/practitioner” (the broadest term that encompasses “organizer,” “planner,” “developer”). One role of the professional is to enable the development of the various organizational entities which promote citizen participation both inside and outside government <sup>13; 16; 34</sup> Professionals

are viewed as essential to the process, but are also criticized as limiting, coopting or controlling full client participation<sup>11, 13, 19,21</sup>.

## GOVERNMENT INITIATED CITIZENS-AT-LARGE “TOP DOWN” PARTICIPATION MODELS

### I. AT THE STATE LEVEL

#### Model A.

**Multiple Methods: State Plans to Manage Growth and Development.**<sup>4</sup> The Federal government mandates that all 50 States examine how they handle residential and business growth in terms of land use, environmental concerns, etc. States are allowed to use a variety of “top down” citizen participation methods to meet Federal requirement. There are six critical choice areas that state level government planners have to make in designing local participation programs: 1) *administration and staffing* as to type, amount and responsibility of staff; 2) *objectives*- how to seek citizen involvement; 3) at which *stage in the planning process* to have them involved; 4) *citizen targets*- the types of stakeholders identified to participate; 5) the *techniques and methods* to use; 6) the type of *information* to provide to the citizens, and when and how to disseminate it. Conditions for Success: The Government achieved greater local participation when the planners used: 1) *two way processes* to engage the public; e.g. in **pre-planning visioning workshops, community forums, surveys, meetings** with a range of groups and constituencies; 2) *informal and formal structures*, meaning networking and outreach beyond the formal structure; 3) *greater numbers of staff and greater proportion of staff time* devoted to the implementation, 4) the ability to hire *consultants*, and the provision of *staff training*; 4) *multiple types of information* provided to citizen leaders as well as working with them to create their own information; 5) *multiple communication technologies* along with direct and indirect outreach; 7) educational workshops to citizens that allowed for *alternative planning designs*; and 8) *participation which started at earlier stages*. Outcomes: The best implementation of citizen participation in State Plans at the local level happened when detailed guidelines were provided by State; when there were strong positive incentives to participate such as providing extra resources to localities; and when there were also negative penalties for failure to comply, i.e. withholding of some financial revenue to the locality. Challenges: The more formal organized constituencies participated more in the process; neighborhood groups were represented least. Local governments with wealthier constituencies and larger communities participated more; planners still wanted to main control.

### **Model B.**

#### **Citizen Panels: <sup>9</sup> Case Study in the State of Minnesota.**

Citizen panels emphasize a structured “top down” citizen participation model. This means State officials are proactive and selected people to participate in a deliberate process. Methods: The State established a two step planning process of intensive participation: 1) a systematic random and stratified survey on environment and agricultural issues distributed to all relevant stakeholders selected from lists of hundreds of organizations and individuals). They weighted those with greater stake in outcome more heavily; 2) they held 5 regional meetings of 4 days each, and 1 statewide for 2-3 day sessions with 60 representatives; 3) They used advocate representatives who were known experts from organizations working on the issues, along with staff input, to assure various alternatives were represented; 4) They paid the citizen panelists a stipend. Outcomes: 1) They obtained greater participation from a wider range of people than when they just put out a call for participation and waited for people to come (e.g. a public hearing model). 2) From the government perspective, it was not open to manipulation from special interest groups. 3) It was considered a success when the criteria included process measures rather than a particular result. Conditions for Success: accurate and meaningful information; sufficient time to learn and reflect on information; a hearing format to learn about issue; different views given adequate representation; a facilitated process to help reach decisions; perceived flexibility and fairness; an orderly agenda; well trained group facilitators. Challenges: Citizen Panels receive legitimacy if their recommendations or outcomes have a high probability of being followed. Otherwise it is hard to sustain participation. Those government and participating groups who liked the recommendations, thought the cost was worth it. Others questioned the cost effectiveness.

### **NON-GOVERNMENT/VOLUNTARY OUTSIDE GOVERNMENT “BOTTOM UP” INITIATED MODELS**

#### **Model A.**

**Community-Based Organizational Structure <sup>30</sup> A Case Study of a local Citizen Organization in a Small City.** Begun as a result of a community analysis (needs assessment) conducted by a University, a need was identified for a structure and process to determine goals and direction for the city. It became an organized approach to facilitate coordination, compromise and conflict management processes. This city had many divisions, rapid growth, and competing loyalties and leadership. The organization named “GOALS” was created as a vehicle through which individual citizens and citizen group representatives come together on continuing basis to set goals and recommendations regarding local problems and issues. It included a diverse Board of Directors of the various identified stakeholders. Federal funds were available to hire a staff person. Conditions for Success: 1) A total planning model that brought together special and, sometimes competing groups; 2) Not being

government sponsored was a plus; 3) The laid-out goals and structure allowed for openness and a trust-building process; 4) Paid staff was essential; 5) Representative and direct participation of additional citizens was done through the establishment of Task Forces; 6) Board of Directors had credibility, a good reputation, and access to decision-makers; 7) Staff assistance from University was essential; 8) The need for an established set of Guiding Principles to keep the processes fair and orderly; 9) The three Task Forces established each developed specific outcomes-taxation on older persons, programs to address juvenile crime; a restructuring of county government. Challenges: 1) Relationship to government was not direct; the GOALS Board of Directors had influence with local government, but did not have authority to make decisions on implementation; 2) Continued funding will be needed for staff and administration; 3) The relationship between the Board and Task Forces needed to be clarified when differences arose about recommendations. The solution reached was to release the TF reports with dissenting opinions; 4) There is a continuing need to assure the participation of traditionally under-represented groups to maintain credibility and representativeness.

#### **Model B.**

#### **Mixed Government-University: Visioning and Sounding Board Structure** <sup>30</sup>.

**A Case Study of a mechanism of citizen participation in a small city.** It was begun by the City Manager, the top administrative leader appointed by an elected City Council. Goal: to increase number of community residents involved in the community participation process; to tackle important community issues and make recommendations to the City Council. Methods: A University Extension program was invited to organize public policy education teams. They conducted trainings focused on public policy decision-making (analysis), and skills needed for implementing the information within a group context (communication). They used a 5 part problem-solving model for decision-making. Both citizens and Departmental staff at all levels participated. They recruited 75 citizens to the "Vision 2020 Sounding Board," plus 12 City Dept. managers. Two cycles were completed. Conditions for Success: 1) Sustained commitment over time was essential; 2) Visions 2020 was used as an independent forum for discussing issues before citizens and government took sides; 3) The process defused "hot" political issues e.g. banning teens "cruising"(driving cars) in the downtown area; 3) Continuous evaluation from all participants; 4) Individuals learned transferable skills; 5) The Sounding Board was sustained in less intensive way, with updates provided by the City Manager's office. This model has been replicated in 6 other areas. The City managers notes: *"More knowledgeable problem-solvers, make more informed decisions, ...a core tenet of the democratic process."*

#### **Examples of Other Models**

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**From the USA:** A county government involves citizens from low income, at-risk neighborhoods in health planning <sup>11</sup>; environmental planning at County

level <sup>19</sup>; citizen priority boards used in several cities <sup>24</sup>; citizen surveys in budgetary and policy-making processes <sup>33</sup>.

**From Other Countries:** A neighborhood decentralization structure mandated nationally and implemented in the Italian City of Bologna <sup>26</sup>; local government planning boards at provincial level in Ontario and Quebec <sup>17</sup>; neighborhood planning structures in Canadian City of Winnipeg <sup>7</sup>; community and economic development in Wales, UK <sup>32</sup>.

## **FACTORS CONTRIBUTING TO SUCCESS AND FAILURE OF CITIZEN PARTICIPATION**

The following are sets of principles learned through experience that increase the probably of success as viewed by the participants and/or by external evaluators. Most of the factors have been identified in the literature or have come from the practice of the author and other experts. The factors are targeted both to government and to “the community,” that is, those individuals or groups organizing clients and/or citizens.

### **PRE-CONDITIONS FOR SUCCESS**

#### **A. At the Government Level**

##### **“Top Down” Government Mandates, Philosophy and Leadership**

- Human and social rights should exist as prerequisite for exercising citizenship and citizen participation; a starting point is the recognition of exclusion of some groups/voices. There must be a fundamental acceptance of access to government by all citizens as a civil rights issue <sup>14 22 ; 17d; 5d</sup> and there must be a full commitment to the process, and a belief that the community has assets, clients have rights and expertise to share <sup>14d; 18d</sup> ;
- There should be a legislative or legal directives/requirements for citizen participation, a mandated recognition or approval by some

government body. It works better when there are provisions for enforcement<sup>26; 34; 4;</sup>. And there must be staff willing and resources to enforce guidelines and procedures<sup>34; 4</sup>.

- The role of political and administrative leadership is essential. First is the preparation of the government agency and its infrastructure for changes<sup>11; 6; 14d</sup>. The commitment and competence of executive-level leaders must be evident<sup>30; 9</sup>. There must be top down and sustained support<sup>11; 10d</sup>. These top level staff become role models with other public officials, are messengers for framing public issues, identify additional skills needed, and establish processes for engagement<sup>6</sup>

### Staff Leadership

- A well trained staff with good process and communication skills<sup>4; 9; 30; 14d;</sup>, is essential<sup>14d; 10d</sup>. They must be able to build credibility and trust with multiple constituencies,<sup>19</sup> especially to understand, relate to and accommodate needs of special and isolated communities<sup>17; 4; 9; 30 ; 9a; 14a</sup>.
- There needs to be sufficient staff and enough allocated staff time and resources.
- Staff members themselves must feel empowered—with proper training, emotional support and opportunities to participate in organizational decision-making<sup>16</sup>.
- Staff needs flexibility to involve residents; therefore, the government agency/department must be able to have adaptable rules and regulations (e.g. who to hire; hours when meetings held)<sup>11; 30; 1a; 5a; 4d</sup>.
- Staff mindset may need to be changed in order to respect and view citizens/clients as active collaborators and partners rather than as passive recipients of service, apathetic or obstructing a plan<sup>16; 26; 33; 3d; 6d; 18d; 10d; 1a; 7a; 8a; 9a; 10a ; 18a; 22a</sup>.

### Relationship with Client/Citizens and Citizen Structures

- Provision for resources including financial expenses to encourage clients/residents must be made, e.g. transportation, child care, food-incentives, stipends to compensate for time off job and expertise; etc.<sup>11; 30; 6d;</sup>
- Citizens must have early and open access to staff and decision-makers<sup>24; 19; 34</sup>. The importance of accurate and understandable information—in language of consumer can't be stressed enough<sup>7; 19; 5a</sup>.
- Structures that allow an open and fair process are an imperative<sup>9</sup>. Participation becomes more meaningful when it begins early in process- at pre-planning or visioning stage<sup>4; 34; 7</sup>.

- The most common and recommended structures are formal entities such as Commissions and Advisory Boards, valuable for their sustainability and public recognition<sup>2; 19; 6; 26</sup>. The need to develop mutual projects to demonstrate commitment and tangible outcomes are recommended as a process begins. The importance of these structures is elevated when there is public recognition given to them through press, conferences, public awards.
- Staff need to provide or obtain training for citizens/clients in a variety of process, political and technical skills and<sup>3d; 12d; 10d; 7d; 2a; 7a; 8a; 10a14a</sup>
- Recognize that most citizen/client groups want and need some professional staff support (social workers included)<sup>6d; 7d; 10d; 11a</sup>

## B. At Community/Citizen Level

### Internal Relationships to Build the Citizen/Client Organization

- Well planned and broad-based democratic decision-making processes, and channels of communication between membership and leadership, with support and feedback from the constituency, strengthen credibility and effectiveness<sup>1; 32; 17; 13d</sup>
- Strong, recognized, competent and dedicated leadership is vital, as is the need to devote time to leadership development and “internal democracy<sup>1; 32; 15</sup>” to build its constituency. Client/community leaders who are passionate, assertive, and knowledgeable are essential<sup>13d; 16d</sup>
- Consumers, particularly those who are vulnerable or lower status, need to be given choice as to whether and in what ways to participate<sup>9d; 10d</sup>
- Groups gain strength from their ability and legitimacy to “represent” the entire community<sup>34</sup>, and to develop a strong constituency base<sup>5; 17</sup>. One way to do that is to allow for multiple views during problem definition phase<sup>22</sup>
- Clients/community leaders should receive training from both inside/government staff and from outside independent organizations. They also need to develop ways to train others (“peers”) in process, political and technical issues<sup>1d; 16d; 18d; 10a; 12a; 22a</sup>

### External Relationships among Client/Community Organizations

- Community/citizen participation has a higher probability of being effective when active, organized grassroots groups already exist, and when there is a history of involvement, a

strategic orientation, and a perceived mandate to participate<sup>26; 13d; 3d; 13d</sup>.

- It is easier to create coalitions when there is a spirit of mutual interdependence and some degree of community solidarity<sup>1</sup>.
- Groups with funding from a variety of sources have increased independence. External funding from foundations and donors enhances consumer control of services and staff<sup>17; 16</sup>. Conversely, groups too dependent on government funding, even for citizen participation aims, have been shown to lose their advocacy focus and become more advisory and service oriented<sup>15</sup>.
- Ultimately, there is a need for proper problem identification or a community diagnosis<sup>1</sup>. This includes framing issues as universal and social, rather than individual, to the extent feasible<sup>16d</sup>.
- Citizens engage better when there is a strong desire or felt need to seek a solution to a problem<sup>27; 1</sup>.
- Large, multi-issue organizations or neighborhood-representing organizations could serve as mediating institutions between grassroots groups and government. They should have the ability to leverage resources from outside the community. Enabling organizations are needed to support grassroots development<sup>13; 15; 35</sup>.

## FACTORS CONTRIBUTING TO FAILURE

### A. Government Level:

- Recognize the existence of institutional, informational and interactive barriers<sup>19</sup>;
- Projects and processes fail when there is an unwillingness to change the structure and culture of leading or participating organizations (government or community)<sup>7; 5</sup>.
- There is also frustration with inflexible government guidelines or rigid structures<sup>19; 1a; 4a; 5a</sup>, and short-term or limited commitment<sup>26; 23</sup> or lack of sustainability<sup>22; 4a</sup>.
- Citizen participation is problematic when there is lack of support or commitment from government staff. This has been seen in patronizing attitudes, or what has been called the “professional-resident divide”<sup>11</sup>. Consumers or residents are perceived to limit efficiency, to lack knowledge and capability, and to generate conflict<sup>17; 19; 29; 3d; 6d; 9d; 10d; 9a; 11a</sup>. This schism is increased when racism and other distrust factors emerge between community and government<sup>29</sup>.

- Staff are unwilling to give up (some) control or share power, which stifles creative processes and fosters tensions<sup>4; 7; 3d</sup>. This is often manifested by an unwillingness or inability to communicate or share information in a timely or understandable way<sup>7; 17; 19</sup>.
- When staff promote their own plans or support a segment of the community, rather than support a more democratic participatory model, they undermine citizen involvement<sup>29</sup>.
- Professionals of color or professionals who come from the same communities that are being invited to the table, can be conflicted because of dual loyalties; they may be viewed in a bi-cultural context as “outsiders within”<sup>11</sup>.

## B. At the Community Level

- Historical divisions, competition, ideological and other differences (e.g. race, class, age) and distrust among different groups within the community, make the process of CCP more difficult<sup>29; 11; 5a; 16a</sup>.
- There may be exploitation of those differences by one segment of the community, or by outsiders (“divide and conquer” strategies). There are examples of exploitation of community participation process by pro-business or other established sectors of community<sup>29</sup>.
- Residents/clients often have different priorities from government or professionals<sup>11</sup>. This can frustrate both groups.
- Lack of funding or the lack of diverse funding beyond government grants, inhibits consumer control<sup>16; 15</sup>.
- Residents themselves lack consistent participation in citizen processes for a variety of reasons, making it difficult for continuity and for building a sustainable organizational base<sup>32; 24</sup>.
- Citizens don’t participate because of the perception or reality of cooptation<sup>24; 23; 13d</sup>; fear of intimidation<sup>4a; 10d</sup> or “tokenism”<sup>4; 14a; 24a</sup>.

## CHALLENGES TO EFFECTIVE CITIZEN PARTICIPATION

In spite of the many reasons for and positive experiences with citizen participation at the three levels of government, there are limitations to a mandated model. It is beyond the scope of this paper to examine all the studies and reports, but clearly there is a wealth of experience where disappointment and distrust was created, and where clients and citizens were either disillusioned or coopted. Government leaders themselves recognize their inability to engage

and sustain participation, especially from a diverse group of clients/citizens. They have also been critical of citizen groups who they say represent only their own narrow interests. Client groups are critical of government who support citizen participation in only superficial, tokenistic ways.

“Top down” citizen participation is neither the solution to strengthening communities and creating more vibrant democracies, nor is it a diversionary force that prevents citizens from gaining more power and control by organizing from the outside (“bottom up”). It is clearly somewhere in the middle as there both positive and negative outcomes. As presented earlier, there are different meanings and rationale for client/citizen participation <sup>19</sup>. Therefore, it is important that those involved in the process to balance expectations and reality with respect to level and scope of decision-making.

There is a need to recognize the inevitable tensions between what the citizens might demand (control) and what the government or agency might only be prepared to offer (advice) <sup>2; 20a; 18b</sup>. Studies show that there is a greater sense of trust and satisfaction felt by those citizens who have mid-level expectations, neither feeling like tokens nor expecting total control <sup>8</sup>. There is clearly a danger of building false hopes on part of citizens as to outcomes, and of too low expectations on the part of government officials or agency directors about the value of involving clients/citizens.

Neither the “community” nor the “government” should be treated as monoliths. There could be as many differences within each of those entities as there are between them. There will be a diversity of beliefs inside each sector about CCP. The challenge for both sectors is to define and seek the “common good” or the “public interest,” and to balance the views of all affected interests, including public-at-large <sup>8; 2; 20; 22</sup>. There must be recognition of differential power dynamics and status of those entering into collaboration or partnerships and to minimize where possible <sup>29</sup>.

Finally, it is important to recognize that there are limitations to both the “bottom up” and “top down,” when it comes to complete representation; rarely do those inside or at the top represent the “average” citizen or the lower income residents, but neither do those from the outside or from the bottom. Both government and community organizations inside and outside the system could ignore important segments of society while purporting to represent them.

## CONCLUSIONS

In order to promote and successfully implement citizen participation, there needs to be: commitment, competence and resources provided by and coming from government. From the clients and citizen end of participation, there also needs to be a commitment of time, demonstrated or acquired competence, a

willingness to play by the rules, and an ability to connect with and be accountable to other clients/residents.

The best democratic system of CCP can be achieved through mutual efforts of government reaching out through citizen participation programs and citizens reaching in through community development and voluntary programs <sup>21;</sup> <sup>18d</sup>. There must be an acceptance that both consensus and conflict strategies are inevitable, and sometimes even necessary or desirable <sup>16; 19</sup>. Everyone needs to recognize that there are both opportunities and obstacles to effective CCP, and to be visionary and realistic at the same time. There must be an acceptance of the fact that voluntarism/ “bottom up” and institutionalization/ “top down” methods are not mutually exclusive <sup>26</sup>. There is a need for mandated structure and for an openness to allow a creative process to unfold. The watchword is to proceed with cautious and planful optimism.

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#### **TERMS OF M.O.S.A. AGREEMENT:**

The Contract with MOSA included the following:

1) Identifying the types and levels of involvement of a variety of welfare clients in planning, implementing and evaluating services, and in developing and reviewing policies and programs, focusing predominantly on New York City, but going beyond as feasible. Because of access to colleagues and the internet, several models from outside New York were able to be included.

2) Reviewing existing knowledge on the topic to include a brief review of the literature on the topic: articles and monographs in the professional research and evaluation literature, government documents and other materials available to the public, and selected websites. Over 100 were reviewed, catalogued and abstracted. More than 30 experts (professionals, government officials, and client leaders) were interviewed, including individuals and organizations who have designed, implemented or evaluated client/citizen participation models.

3) Documenting a variety of models of formal and informal client and community resident participation based on neighborhood, agency, and service or population sector. The areas specifically identified include: general citizens in a community; and four specific targeted client populations: child welfare parents; the physically and mentally disabled including the mentally retarded/ developmentally disabled and the mentally ill; the aged community of senior citizens; and welfare/low income clients, particularly those receiving government benefits or who are vulnerable due to economic or social circumstances.

Commentary: There are differences in the amount of information reported in the various sectors of citizen/client participation, with huge discrepancies among them. For example, there is very little written on welfare/low income “clients,” and almost nothing on the parents whose children are in the child welfare system. There is more description about programs than there is evaluation on the processes and outcomes of citizen/client participation (CCP). The area with the most literature is on participation by citizens-at-large. [A complete annotated bibliography will be provided as an attachment to this Report.]