# The Need for Community Participation and Oversight in the Special Needs Service Delivery System

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As in the era institutionalization, the current service system providing community-based supports for individuals with intellectual disabilities (ID) has become increasingly self-serving and financially top heavy. Currently, the bulk of the funding despite the current needs-based approach to services, ends up supporting and perpetuating the service delivery system. The support for individuals at a direct needs level appears to have been minimized with the growth of the provider structure. The corporate culture associated with the needs-based community support structure appears to have maintained the control and choices originally meant to go to the individuals and their families. In addition, the services that are provided are unequally distributed based on eligibility standards, level of needs, yearly legislative budgets, and government priority lists.

This article is proposing the need for the development of a knowledgeable, informed citizenry to act as a conflict free and socially inclusive systemic watchdog group. The primary mission of this group would be the redirection and equalization of community supports and services to better service and empower all individuals with ID directly and/or through natural/family and community supports.

One would be hard pressed to find any social credence in a return to the institutionalization of individuals with ID. One would also have difficulty denying the critical impact the role of grassroots parent advocacy movements had over the past 50 years in the success of the depopulation of state run institutions. With this social movement came the eventual establishment of community-based, social, educational, and economic avenues for thousands of individuals providing opportunities from segregation through inclusive lifestyles. One would be naïve in thinking this process could have occurred at all without the major changes in Medicaid funding. Along with this came a major shift as well from program- to needs-based funding. Not only was this the right thing to do, it was at the time the less expensive thing to do.

For eligible individuals, Medicaid changes allowed for the redirection of institutional Medicaid funding from institutionalization to community-based funding (known as Medicaid waiver funding /waiver funding). Over the last 40 years such changes have transformed the lives of thousands across the state allowing them access to live and work in the communities they were born in. Today support service provider agencies provide a defined array of supports and services (known as service definitions).

These services include residential supports, day program supports, employment supports, behavior support services, adaptive living supports, as well as numerous other supports.

The depopulation of state institutions brought with it a change from program-funded programs to needs-based funding. Program funding of institutions and the related historical abuse was certainly a catalyst for such a need. The rational for individual needs to determine the funding as opposed to program allotted funding determining the support to an individual had to do with choice and control. The expectation was that if individual needs for services and supports was tied to funding, individuals would be availed more control and choice over the services they received.

Philosophically, the State of Pennsylvania Office of Developmental Programs (ODP) has, and continues to promote the need for individual control and choice through promotion, training, policy, and regulation. This longstanding philosophy developed by ODP is known within ODP as "Everyday Lives." "The fundamental concept of 'Everyday Lives' is that with the support of family and friends, individuals with intellectual and developmental disabilities decide how to live their lives; what supports they need; and how they want to spend the money in their individual budgets. It also means that they are responsible for their decisions and actions.[1]"

Unfortunately, the corporate culture associated with needs waiver funding continues to allow the domination of choice and control to fall into the hands of Medicaid waiver funded providers.

Over the last 25 years this corporate culture in the community-based services model has resulted in the emergence of a "Medicaid waiver sub culture." This culture has and continues to segregate and marginalize individuals and families both outside and inside of the Medicaid umbrella in need of supports and services.

Ironically, as in the era of institutionalization, the current service system for individuals with disabilities appears to have become increasingly self-serving and financially top heavy. Further investigation is clearly needed.

In the past, parent groups have successfully advocated for individuals with ID but as time passed these groups have become funded and entangled politically by the service system they initially fought against.

This article is proposing the need for the development of a knowledgeable, informed citizenry to act as a conflict free and socially inclusive systemic watchdog group. The primary mission of this group would be the redirection and equalization of community supports and services to better service and empower all individuals with ID directly and/or through natural/family and community supports.

Services for individuals with ID generally fall into three categories. those not registered at all, those with medical waiver funding, and those without Medicaid funding (known as base funding).

Current estimates are only one-third of all individuals with ID are registered with the current services system. Rational for non-registration is unclear. It has been suggested to appear in some instances as not worth the time given the perceived benefits. Other suggestions appear to be cultural in nature especially within already marginalized populations.

Of those who are registered, there is a wide gap in the services and supports received by individuals who are and who are not receiving Medicaid waiver funding.

To receive any type of substantial or long-term services, Medicaid funding is required. The collective Medicaid waiver funding for individuals who receive Medicaid waiver funding supports the current provider system across the state.

Within the Medicaid waiver funding for services are further gaps in attainable services based on the type of Medicaid waiver one has secured.

Originally, Medicaid waiver funding was based solely on the needs of the individual and generally reserved for individuals coming out of state institutions (known as the consolidated waiver). This consolidated waiver was initially cost effective. In some situations, it allowed for additional funding for additional community placements. Over time this evolved with the emergence of a second waiver with a financial cap of $33,000 (Person/Family Directed Support Waiver) and most recently a third waiver with a $75,000 cap (known as the community waiver). The result of these changes enables limits to be placed on needs-based services and on the type of waiver an individual obtains.

To compound this situation, it appears once an individual does manage to obtain Medicaid waiver services the proportion of funds supporting the provider structure appears to far outweigh the funding of actual direct services provided to the individual (exemplified below).

Registered individuals not receiving Medicaid funding receive county funding that provides minimal and limited services known as “base” funding. Unlike Medicaid funding, services-based funding is limited to case management services and family support services. Generally, these services are limited to less than $1,000 per year for individuals who are approved.

Individuals not receiving Medicaid funding are unable to access the services and supports provided by Medicaid. These services include residential and day services, behavior services, support staff services, and companion and respite services.

Individuals not receiving waiver funding are put on a state-wide priority list to receive waiver funding based on urgency of need.

Over the last 20 years, this waiting list has, and continues to number in the thousands and is subject to yearly funding shortages associated with the Medicaid contract with the state and the willingness of the state legislature to appropriate matching funds.

The result of this structure makes entry into Medicaid funding extremely difficult for anyone who is not in need of immediate emergency services. Many individuals have been waiting years. In addition, those who are on emergency status are subject to competition with others in the same status for services based on their severity of need and the number of available waiver allocations in any county in any given year.

This current funding process appears to have created several gross inequalities on the value of an individual’s needs by putting varied amounts of funding on an individual’s need for services. Some ranging from less than $1,000 per year to others that are as high as $700,000 per year.

A review and contrast of any budgets for individuals with ID readily exemplifies this inequality. For example:

In one instance, an individual is funded by the Medicaid waiver and the provider is receiving $58,000 per year to provide support services for an individual. The direct services to the individual consist of 35 hours of services by a support staffer at $11 an hour with no benefits. In a second situation, a budget of $337,000 is utilized for an individual who lives in a group home.

In a third instance, an individual with ID with a secondary mental health diagnosis is receiving more than half a million dollars in funding per year.

In a fourth instance, an individual has a Medicaid waiver that is capped, thereby forcing the individual in need of both day services and home services to choose between which of the two services they require most.

In the same review, one can easily see the lack of funding availed to an individual who is not receiving Medicaid waiver funding and subject to local limited program-based funding. In one instance, an individual exhausted her yearly allotment to buy a bed.

## Systematic Issues Related to Inequality of Services

Other significant and longstanding systemic issues related to the inequality of current supports, services, control, individual choice, and funding include the following:

### Ineffective Direct Line Supports

The lack of supports and funding for direct line support staff has been problematic since the beginnings of the movement for individuals from institutions to those in community placement. Compounding this issue appears to be the continuation of the culture of mistrust of the service system and providers for family members as active participants in the direct care of their loved ones.

## Lack of Understanding of Current Supports and Services

All one needs to do is talk with a family member or relative with a disability to see the lack of understanding of the current support system by the general public. This appears to continue to be an issue with local and state law enforcement organizations.

A bureaucratic bubble appears to exist that feeds into making those outside of the bubble dependent on someone on the inside to gain any kind of understanding.

In a similar discussion, one would find members of the general public who have no life experiences with individuals with ID generally lacking any knowledge or understanding of the current (or lack of) services and supports available to individuals with ID.

Despite geographical and legal integration into local communities for individuals with disabilities, it appears social integration continues to be a challenge.

## Justification for Needs-based Funding Outcomes

The definition of Medicaid waiver services implies the following:

"Consolidated Waiver Home and Community Services are direct services provided to individuals who need assistance in the acquisition, retention, or improvement of skills related to living and working in the community. These services may only be provided through the waivers when the AE (authorizing entity) determines they are necessary to prevent institutionalization.[2]"

It appears that if services are contingent on skills to live and work in the community, the need for justification of services is needed for individuals to live outside of an institutional setting.

With this said, it would appear to be in a providers' best financial interest to maintain an individuals' current need. Alleviating any need for acquiring, retaining, or improving services would jeopardize the possibility of institutionalization, and with it, a need for funding.

## Compliance Monitoring and IM4Q

Monitoring of services and supports are problematic in several ways. The first being the time lines associated with county and state monitoring. In these situations, provider agencies are informed in some cases months prior to inspections with ample opportunities for corrective plans. Secondly, monitoring by supports coordinators (case managers) is subject to frequent staff turnover.

### Predatory Providers

One of the original intents of the needs-based Medicaid waiver model for the ID population was to foster quality and choice of services and supports. Although further investigation is needed, it appears the lack of oversight and regional scarcity of providers may lend itself to the opportunity for some to make a profit from individuals with disabilities.

### Ineffective Supports Coordination

The role of the supports coordinator is to locate, monitor, and coordinates services. These key positions are often filled by well-intentioned, but inexperienced individuals right out of college, and utilized as stepping stones for more lucrative positions within the provider systems. Not unlike an ex-congressman becoming a lobbyist. In addition, the delivery of needs-based services recommended by an individual's support team is often delayed due to numerous levels of bureaucratic approval between, and within, different provider and government agencies.

### Accountable and Conflict Free Incident Management /Abuse Reporting

Current practices allow for a provider to investigate abuse and neglect issues by investigators employed by the provider. In addition, any corrective actions of investigations are also left to the discretion of the provider. Eg., If Joey is hurt by another resident -- unlike you or I -- the police would not be called. The provider would be required to file an incident report, determine if it required investigation, investigate the incidents, and decide on any action needed for correction.

## Community and Residential Segregation

Individuals continue to be segregated within the community setting. Advocacy efforts in the past have secured legal pathways for individuals with disabilities. The need for social pathways through community awareness, understanding, and most importantly, participation, remain lacking. It appears that to this end, one critical stakeholder not in support of community inclusion has been the community at large.

## Growing Concern Over the Diversity of Service, Economic and Racial

Growing concern appears to be developing over the pathway to eligibility for individuals with ID in obtaining services. The current statewide priority list, and the decisions as to who gets the limited services, appears to lack any type of transparency. There appears to be the impression that individuals who are privy to the structure and/or those with political influence and related family wealth have unequal access to medical funding.

### Mental Health

It also appears mental health services for individuals with ID remains problematic. Funding conflicts between Medicaid waiver funding and mental health insurances are often in conflict with each other over payment. At times Individuals with ID are segregated from many current mental health facilities and services. Understanding and services to address the unique needs in recovery for individuals with ID appears lacking in the current mental health system.

### Lack of Available Advocacy Services for Adults with ID.

Individual advocacy for individuals receiving services has been on the decrease. Most advocacy organizations that do provide individual services have limited resources and have begun charging for individual assistance. Systemic advocacy appears to be focused mainly on increases in waiver funding. Services for individuals receiving base funding appears to be stagnant. Little if any effort is being made for outreach in identifying individuals who remain outside of the service system.

## Innovative Solution and Explain How the Model Works.

Effective watchdog group/grassroots movements have, and continue to be, effective avenues for social change.

As noted above, grassroots organizations for individuals with disabilities, such as the ARC, have lead the way in social equality and inclusive living and education for individuals with disabilities.

The need for the development of a knowledgeable, informed citizenry to act as a conflict free and socially inclusive systematic watchdog group is imminent. The primary mission of this group would be the redirection and equalization of community supports and services to better service and empower all individuals with ID directly and/or through natural/family supports.

A shining example of how parent and civic participation can define and change social injustices for the betterment of all was the early educational movement for individuals with ID to obtain the right to education. This early grassroots, parent-driven political movement out of Pennsylvania, now known as the ARC, evolved from a civil rights issue that lead to legal lawsuits. From there the movement addressed federal and state legislation to establish the right to education for all individuals with disabilities, and overtime it caused the depopulation of state institutions for individuals with ID. These effective advocacy organizers found funding through grassroots membership and creative fundraising efforts.

As with most successful social movements the success of their initial cause and advocacy efforts become part of the political landscape. This becomes problematic when advocacy organization membership, participation, and funding is no longer adequate to support efforts.

It appears to many across the state that this has occurred across the disability community, and the need for effective advocacy is currently limited because of the financial marriage between current advocacy organizations and the funding of services for individuals with disabilities. To many it appears the advocacy organizations have become partnered and dependent on Medicaid provider funding.

Initially, these effective advocacy organizations found funding through grassroots membership and creative fundraising. Yet, this does not appear to be the case today, as most are dependent on sister organizations that are funded through Medicaid. In the past, parent groups have successfully advocated for individuals with ID but as time passed they too have become funded and entangled politically by the service system they initially organized to change.

Historically, advocacy organization membership has been targeted toward middle class white communities with leadership roles targeted toward upper middle-class whites. Although this was effective in the past, such segregation over time would make one question the need for a more comprehensive approach to advocacy that is more economically and socially representational.

As noted, this article is proposing a renewed movement of conflict free advocacy to support and safeguard the control and empowerment of choice for individuals with ID and their families. This movement would not be unfamiliar to those of yesterday but would include several additions and new dynamics.

A membership based and funded organization comprised of families and direct care givers (paid and unpaid) could be organized as a nonprofit, free of funding obligations with the current provider system.

The membership might consist of a cross-population of individuals who have interaction and contact with individuals with ID daily. These members might include direct and extended family members, friends of family members, neighbors, local community businesses, political leaders, and individuals providing direct support.

One ideal situation might be a partnership with a for profit or a philanthropic organization. This might alleviate any tendencies over time for any future financial conflicts of interest or buy-ins.

Memberships could be targeted to include all levels of social and economic classes and cultural diversity. The advancement of technology in the past several decades made this a lot more feasible than in the past and it has been successfully utilized by other organizations to promote causes and to get out the message.

Members could be solicited for input on their knowledge, needs, attitudes, experiences, and suggestions on how to better serve and support inclusive communities for individuals with ID. The members and leadership could promote legislation to support all individuals with disabilities without subjection and dependence on the political tide of the annual funding of Medicaid contracts and funding limitations. The leadership could research and publish best practices and monitor current services. They could provide individual and systemic advocacy for individuals with ID. The members and its leadership might act as consultants on policy and regulatory changes to alleviate systemic/bureaucratic barriers to better enhance individual control and choices of supports and services.

In addition, the organizations' members and leaders could monitor current services and supports based on its membership's experiences and compare this information with the values of the "Everyday Lives" model (aforementioned). Membership could foster advocacy for family/parent groups, not unlike those effectively used on a local level, in the improvement of educational services and the promotion of a more positive culture in local school districts.

The model would include promotion of the following:

## The Case for Civic and Community Engagement

Civic engagement and participation has and continues to be a powerful force in creating and maintaining positive social changes within a society. Throughout our history, grassroots and populous movements have over time opened doors for many who had been marginalized. In a capitalistic environment the success of such movements to maintain a balance for social needs over economic progress remains a challenge.

Effective watchdog groups/grassroots movements continue to be effective avenues for social change. As noted above, grassroots organizations for individuals with disabilities, such as the ARC, have lead the way in social equality and inclusive living and education for individuals with disabilities. As with most successful social movements the success of their initial causes and advocacy efforts become part of the political landscape.

Within the context of this article we are calling for a renewed movement directed towards a wider community-based and diverse membership whose active involvement might address needs not currently being met or addressed given the current corporate environment of the services system.

These include:

- The need for transparency;
- Redistribution and redirection of funds;
- Establish level of community standards;
- Diversity of services;
- Eradicate bureaucratic and regulatory segregation;

- Development of community awareness at a local level through education and public promotion campaigns;
- Wider political base that includes members of the community who are aware of and knowledgeable of both the individuals′ and community needs associated with the advancement of true inclusion;
- Further development of, and public acceptance and understanding of, the needs and benefits of inclusive communities for individuals with and without disabilities; and
- Support, expansion, and simplification of access to funding to enable individuals to manage their own services and supports.

The end result of the infusion of community and civic groups as stakeholders committed to truly inclusive communities can continue to lead to an integration of services and supports within the community at large.

Throughout history grassroots populous movement have, and will continue to be, critical elements in the challenges of social change. The segregation and ultimate inclusion of individuals with disabilities into our society continues to be challenged despite significant legal protections and awareness. Segregation has and will continue to lead to inequalities in services and supports. Only with the empowerment of individuals with ID, and support to safeguard the ability to maintain control and freedom of choice in their daily existence, can the vision of an″ everyday life″ become a reality[3].

[1] www.dhs.pa.gov/citizens/intellectualdisabilitiesservices

[2] www.dhs.pa.gov/cs/groups/webcontent/documents

[3] www.dhs.pa.gov/citizens/intellectualdisabilitiesservices