Recruiting, Structuring and Leveraging the CAC

Joanne Siegel

2002 DD Act – Mandates

- Ensuring consumer inclusion and participation
- Breaking down barriers
- Building relationships
- Meet as often as necessary, but minimum of twice a year during the grant cycle

How do you sustain membership, particularly of people with developmental disabilities and their families?

RFK Recruitment Sources

self-advocacy groups

Family members, self-advocates from clinical service program

Bronx DD Council

NYS DD Council

Voluntary Agency Partners

Department of Health and Mental Hygiene

Hispanic Parent Support Group

Keeping CAC Members Involved

- Self-advocates and family members from the CAC participate in conference presentations at local state and regional education conferences
- Participate in training sessions with LEND students and staff
- Make local, state and federal presentations to legislators on topics of service needs and concerns
- Annual trip to Yankee Stadium
- Annual staff/CAC holiday celebration

Structure

- Quarterly meetings- but we maintain ongoing activities with self-advocates and family members
- Staff members report on activities
- DD Partners report on statewide and local activities
- Meeting Focus
 - o Internal organization planning- what do we need as a UCEDD
 - o External advocacy/dissemination/education efforts

Internal Issues/Topics Covered

Current UCEDD activities discussed:

-grant applications

Current research efforts

Cultural diversity

Community activities, education and dissemination

Legislative and advocacy

Leveraging with Network Partners

- Advocacy
 - o DD Councils, IAC, COPA, AUCD, SANYS, AAP
 - Direct support funding
 - Early intervention funding
 - 4410 and 853 schools funding
 - Need for more housing options
- New relationship with Fordham Law School to focus on the social justice needs related to the DD world
- Clinical/Programmatic
 - o Infant-parent-court project
 - o GABI- group attachment-based intervention
 - Care coordination
 - Primary Care Model including mental health