

Minnesota Children's Summit 2005: Smart Policies, Strong Families
Monday, March 28, 2005
Practicing Family Impact Analysis
1:45-2:45 p.m.

Consumer-Directed Community Supports (CDCS)

Goal of session—how checklist can be applied to policies and programs and their impact on families

Guidelines for discussion:

1. Complete family impact analysis does NOT have to be done for it to be beneficial
2. Purpose of impact analysis is to present facts in a logical manner; presentation of facts may not be of our own values
3. Don't need to be experts on issues, idea of exercise is to familiarize w/ impact analysis
4. Equally well-informed people can have different points of views—can help advance impact of analysis
5. Goal NOT to pass judgment on particular program, but to learn skills necessary to look at policies and programs using the impact analysis

CDCS

Start-Oct. 1, 2004

Budget Guidelines:

1. **Full-team developmental disability screening (MR/RC Waiver)**
2. **Face to face long term care consultation screening (community alt care, comm. alt for dis ind, Elderly and trauma brain injury waivers)**

CDCS—home and community based waiver; kind of like patient-choice

CDCS is not in all 87 counties

Current rules have changed—changed Oct. 1, 2004 (this is the newer version)

This Oct. 1, 2004 amendment brings control back to state

Note: reduces budget (at least 50%) if release control...(state...)

Goes over handout—description of CDCS

- Going back, there were a lot of people w/ developmental disabilities in these types of settings
- Government willing to waive certain requirements so could get certain services
 - This was in response to certain things, e.g., cultural differences
- Program is driven and directed by the consumer
- Olmstead(sp?) decision—part of the history—many programs come from people suing the government. It was a civil rights case—Olmstead sued government to get son out of institutionalized care and into the community
 - Result—state(?) said they didn't have enough resources to do that BUT judge said that wasn't enough of a reason
- More people applying for a waiver, but as families came on, needs were different

- Vs. institutionalized model where they were caring for their children AND also trying to find resources in community; in waiver there is a self-determination movement—out of that mvmt, get idea of “Consumer Directed” [kind of like what David Sanders was talking about—federal policy on state policy—trickle down]
- **Main factors/issues:**
 - **1. deinstitutionalization**
 - Debate among attendees—Not necessarily cheaper for deinstitutionalization
 - BUT may be a bigger goal of cost containment
 - Community based supports were not in place (w/ deinstitutionalization) and when you have them in place it costs a lot to sustain them—NO PROOF positive that it is cheaper; Phillip heard that if everyone hears about it and takes advantage of it...what they’ve found is that home and community based services are humanistic and people prefer(?)
 - **2. self-determination**
 - **3. entitlement→waiver (requires advocacy for services)**
 - **4. Cost saving OR costly**
- Let consumer direct their own care—thrust of program
- Talking about system put in place, never had research to say that based on how system is set up, if families had designed system then would be led by providers that had hourly rate, or staffing patterns should be put in place (BASED ON INSTITUTIONAL COST)
 - This is a designed environment that we borrowed from institutional staffing—so when talk about staffing costs, talk about rates
- Keep in mind, this is a young program;
 - Presence of choice
 - Only thing offering is whether you want to manage it or want someone else to manage—IT’S A CHOICE!!! May not be for every family, it’s a choice
 - Rich isn’t sure how much education there is before families make this choice
 - Phillip—there’s a provision w/in CDCS that you can choose it AND can also choose to have a support coordinator (an expense out of allotted amount) who will fill out paperwork, etc.

How family impact checklist can be applied—Goes over checklist and 6 principles (6 principles were reviewed over during lunch and are in people’s packets)

Principle 1. Family Support and Responsibilities

- **Administration and choice can be a burden**
 - Having to be own manager can be overwhelming—example given of really chaotic families

- **Education to parents about admin**
- **Support coordinator offsets admin duties**
- Sometimes w/ government stepping in and providing services it can be intrusive (other people coming in, even though they're there to help)
- There may be divorce in these families
- It seems like there could be lots of ways to make the dollar lasts longer → e.g., "hire aunt" but aunt kicks it back to you; WITH amendment—now parent can get paid to take care of child—for things over and beyond normal—e.g., language therapy provided by parent
- In Dakota county—it struck Gail as middle class—e.g., banking (in poorer neighborhoods that don't even have that many banks, how many individuals keep track of their bank receipts, etc)
 - Ella felt the entire mvmt is middle class in certain ways, parent-education is extremely important (why she went back to entitlement), if parent knows signing up to get supports, low-income people will have burden if not educated w/ what steps to take; entire disability mvmt, lack of people of color; if education of what you're supposed to do, and if it's at local level (e.g., churches, schls)—the whole education has to start at grassroots level;
- Ripple effect—what about families that say, "I want this but I want MFEP which says I have to work 20 hours—what does it do that I'm not at home (b/c trying to get education)—SO THERE'S A CONFLICT
- Program has checks and balances—there are filters there
 - Have to get budget approved—someone is looking at what you're doing

Principle 2. Family membership/stability

- Does it allocate \$ to keep family together? DOES NOT
- **Community integration**—But what Phillip's seen (pre-Oct. 1st system) is in families w/ 2 children w/ disabilities, see it's a huge task to get out of community—will at least pay PCAs way into zoo—BUT after amendment, this wasn't supported
- W/ amendment, making sure county itself holds onto those dollars w/ cost containment—b/c w/ fraud and whether parents will be using \$ correctly is in mind of legislators—RARELY have people just be given public dollars to spend without trying to figure out what spending on
 - Initially wonderful that could direct own care
 - Now there are strings attached
- Does this help keep families intact—Phillip thinks it does—b/c allows flexibility, etc.; does provide respite care

Principle 3—Family involvement and interdependence

- **Isolation**
- Promote interdependence?—Phillip's curious if people who designed CDCS have seen this (PRINCIPLES) b/c there are so many ways that people were addressing some of these issues

- There's a sense that if you don't reach out to agencies that might bring someone in, there's that choice to isolate, maybe not even knowing
- BUT, some families/family members may not want to be involved
- With families of color—do not have extended families like there was 30 years ago; more isolated, sense of isolation; it's a lesson to be learned about health care, how care for family member and standards they see—families at table doing what they can

Final thoughts on using the checklist or CDCS:

- Not easy to do, incorporating policies and how they translate for families—makes you aware that there's a lot to think about when making decisions
- Value—having those questions at the forefront (for families, etc.)
- A lot of this seems to be focused on the “how” and it would be enlightening to have the outcome (this is where we want you to get to); easy to default to the “how”
 - Forms used now for CDCS—starts w/ what do you want to do and gives suggestions
 - Be careful with just focusing on outcomes, especially since we've seen what's happened with school systems going to a strictly outcome-based approach
 - BUT we can use research to say *how* to get outcomes
- Cost containment—the how and what's the unintended effect and consequences—may have weakened family interdependence

Questions:

1. What are the ripple effects?
 - a. Young program, this is going to have ripple effect; retirement group—in order to gain services, have to have diagnosis—have to be strong advocate
 - b. Families of color first aren't on the waiver, so the ripple effect in her (Af-Am) community—communities of color who need this service aren't going to get it—need to be able to put it in a story
2. What might be indirect effects?
3. How policy is written vs. implemented?
4. Spoken and unspoken assumptions of policy?
5. Possible trade-offs?
6. Impact of policy on most vulnerable vs. most stable/resourced?