

Waiting for Services in Pennsylvania



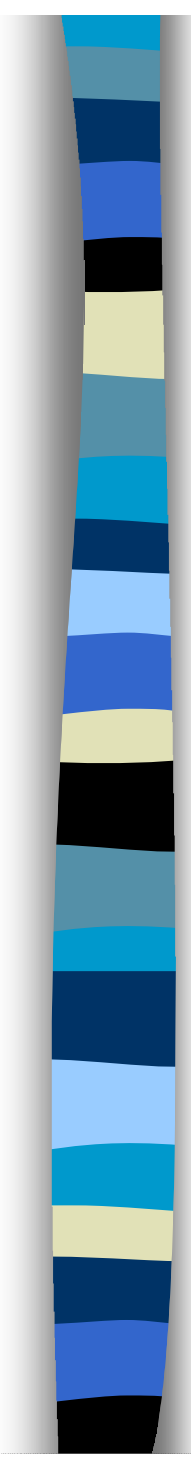
Reinventing Quality

August 1, 2008



Presented By:

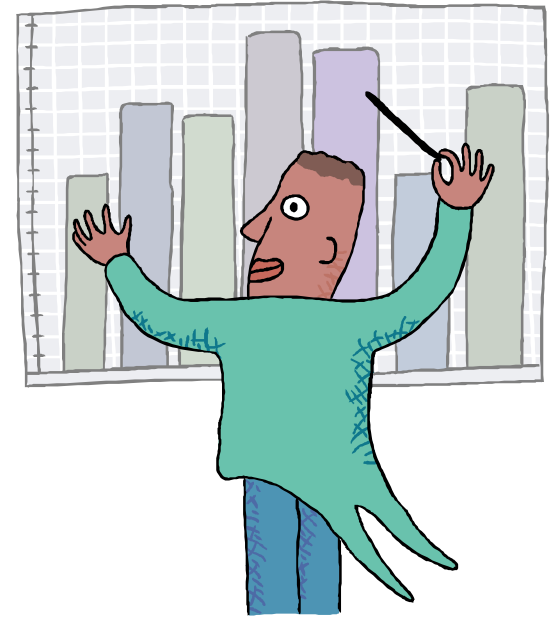
Celia S. Feinstein, Associate Director
Institute on Disabilities
1601 North Broad Street
Suite 610
Philadelphia, PA 19122
215-204-6561
e-mail: shoes100@Temple.edu



Pennsylvania Office of
Developmental Services (ODP)
contracted with the Institute on
Disabilities to conduct a study of
issues related to the Waiting List

Initial Findings

- Inconsistent data collection and tracking processes across counties made meaningful data collection and analysis impossible at that time





Initial Findings (Continued)

- The demand for service is greater than the number of people on the waiting list
- An average of 49% of the individuals who came into service during the year under study were not captured on county waiting lists



Initial Recommendations

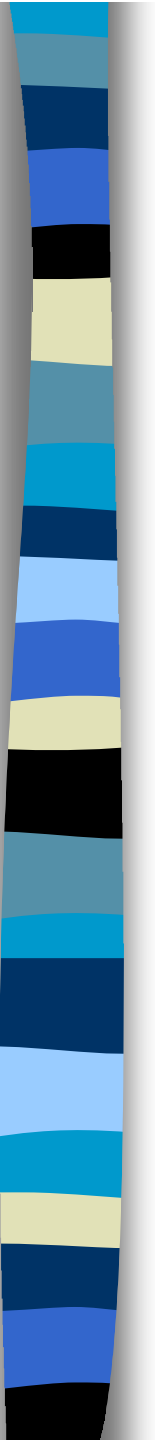
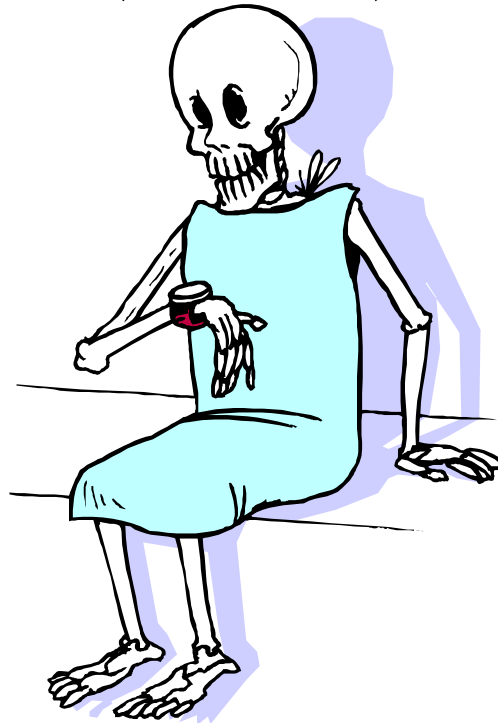
- ODP to develop a consistent definition for the term “waiting list”
- ODP to establish uniform state-wide data collection and tracking procedures for this list



Initial Recommendations

- ODP to develop consistent and clearly defined instructions on how to report data for needs-based planning process

Prioritization of Urgency of Need for
Services for Persons With Mental
Retardation
(PUNS)





Statewide Implementation

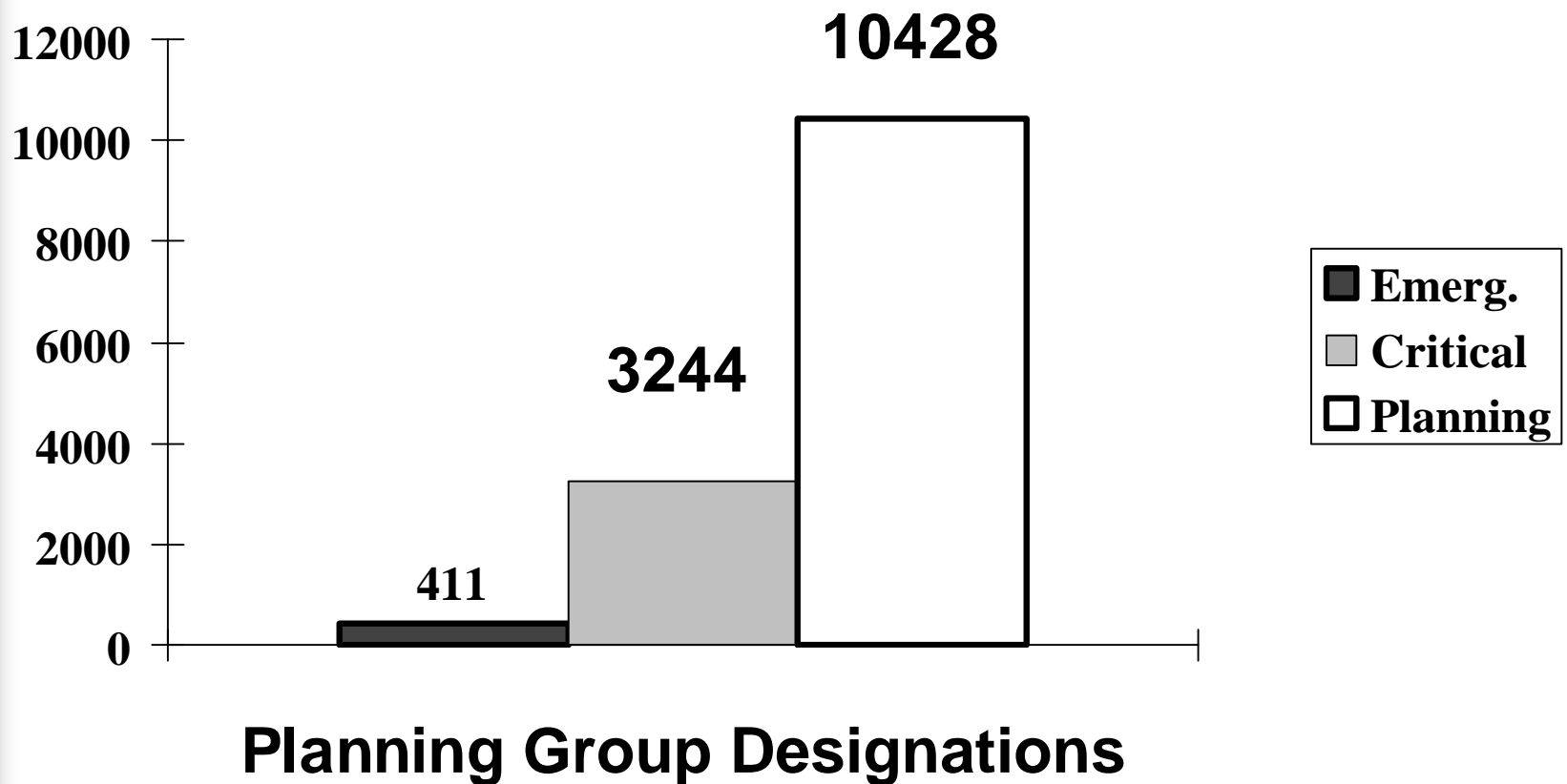
- Each county asked to complete one *PUNS* form for each of the individuals within the county who is identified on the waiting list
- The waiting list is a fluid system. Any data gathered are best considered a “snap-shot” that is useful for planning purposes



PUNS

- Classifications of need: emergency, critical, planning
- Supports received, supports needed: supports coordination, support services, work-vocational-adult day services, and residential services

14,083 People Waiting for Services in Pennsylvania (1999-2000)





Living Arrangements



■ Own home or relative's home	78.2%
■ Some type of supervised living	4.1%
■ Family living and home-based	2.0%
■ Private ICF/MR	1.7%
■ State operated facility	2.2%
■ Other arrangement	11.9%



Summary

- 411 individuals in PA need services immediately and 3,244 need services within the next year
- 90% need day or residential services
- Of the 90%, about half need **new** day services or residential services, and about half need **more appropriate** day or residential services



As a Result of PUNS Implementation...

- The governor requested a work group to develop a waiting list plan
- A state-wide planning group was convened to establish ongoing procedures to monitor the waiting list, and to reduce the number of people waiting for services over a 5 year period

State-wide Planning Group



- Consumers
- Family members
- State organization representatives (ARC, DDC, P&A, UCE, UCP, ...)
- County MH/MR Programs
- Supports Coordinators
- Legislators
- Others (DOA, Governor's Budget Office, DPW)



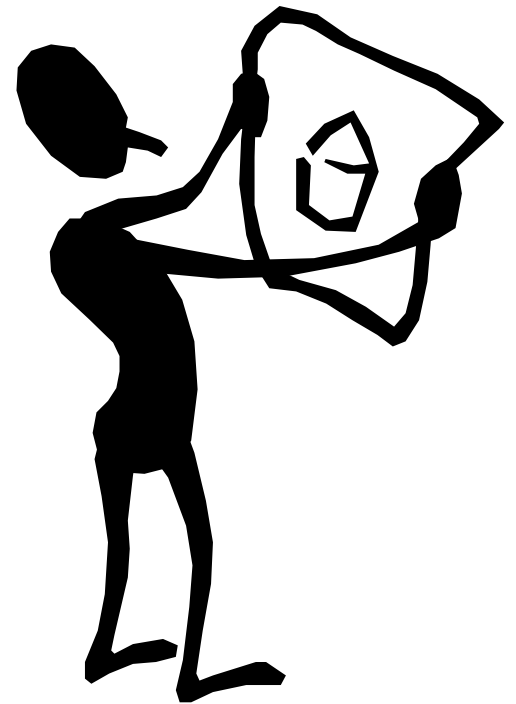
State-wide Planning Group Task

- Modify the data collection instrument
- Establish computerized database capability
- Examine obstacles to reducing the waiting list including provider capacity, availability of professional staff, and direct care staff salary issues
- Make recommendations to the governor regarding a timetable and budget estimate



Product: A Five Year Plan

“A Long Term Plan to
Address the Waiting
List for Mental
Retardation Services
in Pennsylvania”





Principles of the Plan

- Everyday Lives
- Multi-Year Plan
- Self Determination
- Quality services and supports



Recommendations In the Plan

- Service Expansion
- Establish on-going process to review and respond to waiting list
- Increase state and county capacity
- Consumer and family outreach and education



Recommendations In the Plan (Continued)

- Reinvestment to improve the quality of services and supports
- Self Determination
- Preparing for school to adult life transition
- Community opportunities for people in state operated facilities

Results of the Planning Group



Pennsylvania received a Waiting List Initiative from the Legislature for \$853 Million over 5 years (Only the first 3 years were funded due to change in administrations)



Follow-up Data Collection

- Definition of “waiting list” was refined (waiting for services, aging caregiver, projected need, change in residential supports requested/recommended, transition from state center) and timeframe of projected need limited to 5 years
- Service and supports were updated



Follow-up Data Collection

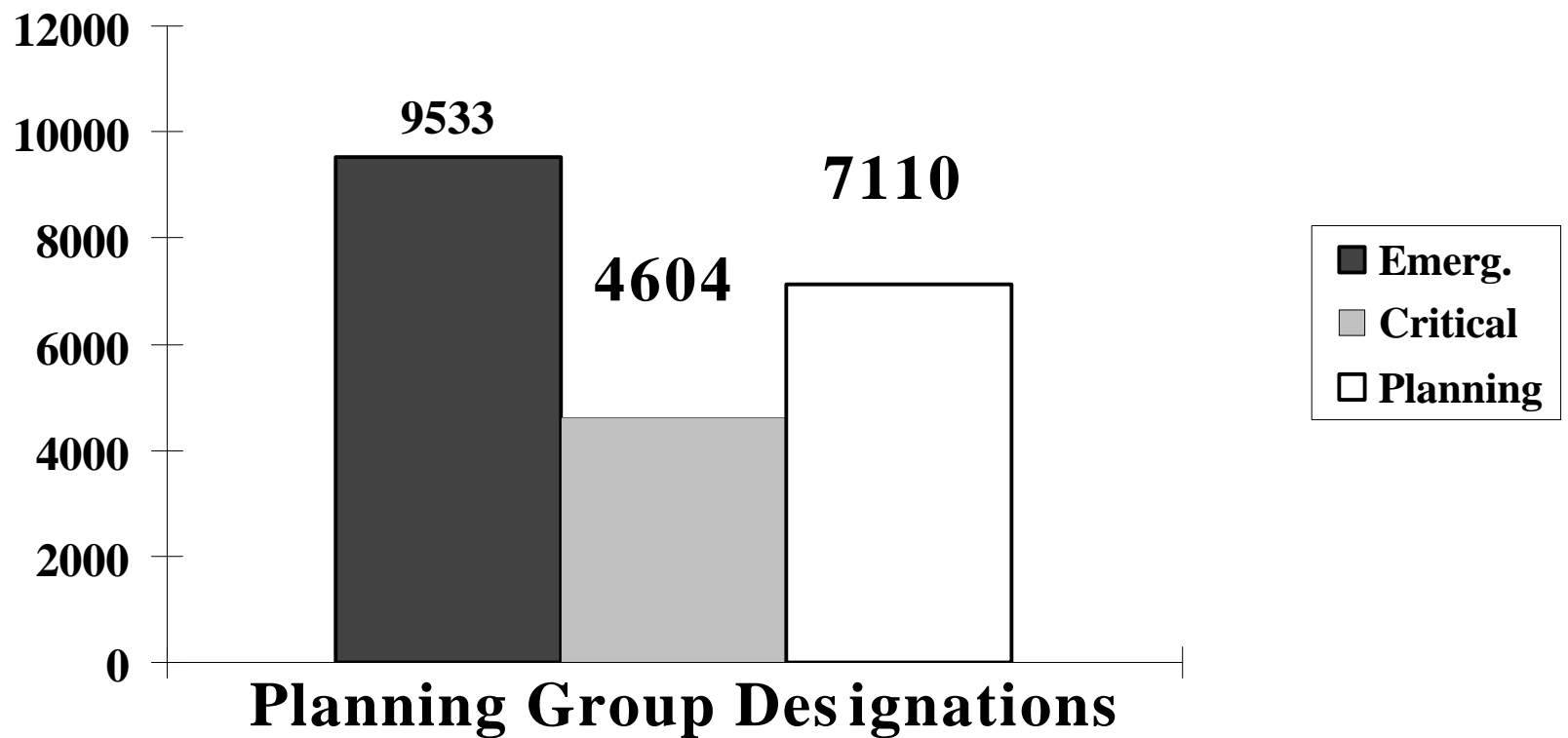
- Collaboration between county and the individual (or their family) in the data collection period was required
- Data collection training offered

Follow-up Results



In 2000-2001, 16,988 people were waiting for service in Pennsylvania (up about 20% from 1999-2000 figure)

What Do the Data Look Like Now? (N=21,247) as of 5/08





What has Happened Since The Initial Data Were Collected?

- Second plan was developed but never approved by DPW – January, 2004
- PUNS was revised and all stakeholders retrained in 2006
- Issue of statewide management of waiting list has been raised
- Issue of how people come off of the waiting list has been raised