

Independent Monitoring for
Quality in Pennsylvania:
What Do The Data Say?

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Celia S. Feinstein, Associate Director

Robin Levine, Assistant Director

Institute on Disabilities/UCEDD

Philadelphia, PA 19122

215-204-1356

Shoes100@temple.edu

Dana Olsen

Office of Mental Retardation

Harrisburg, PA

Dolsen@state.pa.us



Origins

- OMR Multi-Year Plan
- Lack of Data
- HR 187 Hearings
- DD Council Citizen Monitoring
- Legislative Recommendation
- Outcome Findings from Other Sources
- Embreeville Settlement Agreement



Intentions

- Local Monitoring by Independent Bodies
- More Faces in the Community
- Systems Monitoring
- Data Analysis at County, Provider and Service Type Levels
- Data-based Systems Change
- Capacity Building?



Stakeholders

- DD Council
- University Center
- Protection and Advocacy
- State DD Agency
- Providers
- Self-Advocates
- Community Parents
- Institutional Parents
- County Administrators
- Direct Care Workers
- Unions
- Arc and UCP



Planning Recommendations

- Conducted by consumers, family members and regular citizens
- 50% Consumer and Family Boards
- Quality of Life over Human Service Compliance
- Independence from System
- Standardized Instruments and Reports



Relationships to Other OMR Initiatives

- Licensing
- Licensing Reform
- “Transformation Process”
- Provider Profiles
- Web-based Information on Licensing, IM, and Incident Management
- Quality Management System



Timelines

- 1997 HR 187 Hearings
- 1998 DDC and OMR-PAC Process
- 1999 First 19 Projects - Residential
- 2000 Integration with Core Indicators
- 2001 46 Projects, Day and Residential, Institutional and Community, Systems Integration, Web-based Reporting



Statewide Steering Committee

- Established in 1999
- Majority Consumer and Parent
- Non-voting representatives from DDC, PPA, UCE, County MH/MR Board, Direct Care, County Administrator, Providers
- Approves Project Independence
- Issues Reports and Recommendations



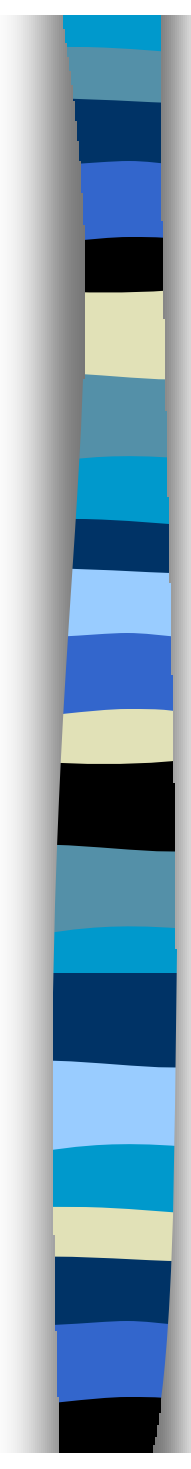
Instrument Development

- What exists in PA?
- What exists in other states and nationally?
- What needs to be developed?



OR and OK: Advocates Involved in Monitoring (AIM)

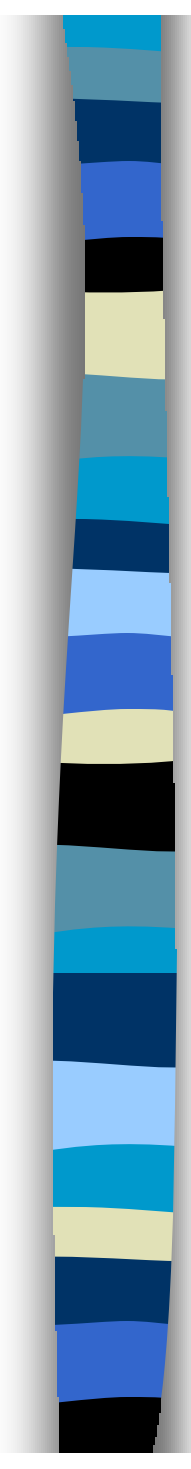
- **Goal** - Trying to enhance service quality
- Teams of volunteers including people with disabilities, families and interested others visit people receiving supports



OR and OK Advocates Involved in Monitoring (AIM) cont'd.

■ Issues

- No info with which to make choices regarding providers
- Existing QA doesn't
- Existing processes don't address issues important to people



OR and OK Advocates Involved in Monitoring (AIM) cont'd.

■ Areas Addressed in Surveys:

- Relationships
- Community Involvement
- Recognition of Rights
- Protection of Health and Safety



Maryland's Ask Me Project

- Interviewers are people with disabilities who are paid
- Interviewers work in pairs with a support person available if necessary
- Instrument developed with significant input from people with disabilities



Ask Me, Cont'd.

■ Areas Addressed:

- Satisfaction
- Healthy, Safety and Dignity
- Community Integration
- Employment
- Transportation
- Independence



PA: Independent Monitoring for Quality (IM4Q)

- Annually, IM4Q surveys approximately one-third of the people living in licensed residential settings
- Data are also collected for individuals who are part of the National Core Indicators Project (NCIP) sample (may be living in licensed or unlicensed residential settings, with families or independently)



IM4Q Cont'd.

- All county MH/MR programs were required to begin IM4Q projects by FY 1999-2000
- This presentation summarizes data from the second complete round of data collection (FY 2001-2002) – 5659 interviews were conducted and analyzed



The IM4Q Survey Instrument

- Satisfaction
- Dignity, Respect, and Rights
- Choice and Control
- Relationships
- Inclusion
- Impressions of the IM4Q Team
- Family/Friend/Guardian Survey

Note: The first two sections could only be answered by the people themselves. Generally, between 43% and 66% of the people were able to respond in these sections

Satisfaction

- In general, people were satisfied with where they live (90%) and with what they do during the day (91%)
- 92% of the people were happy with staff at home, and 92% were happy with staff at work or day activity





Satisfaction

- People said less often that their housemates are nice (84%) as compared to staff at work (92%) or at home (92%)
- 77% of the people reported usually feeling happy
- 59% reported never feeling lonely (3% reported always feeling lonely)



Satisfaction

- 70% said people always knock and wait for a response before entering their home
- 66% said that people always knock and wait for a response before entering their bedrooms
- 80% of the people always have privacy when they want it



Satisfaction with Work/Day Activity

- 84% of those who work felt they worked sufficient hours
- 13% would like to work more hours
- 3% wanted to work fewer hours

Dignity, Respect and Rights

- Most people were never afraid at work (83%), at home (74%), or in their neighborhood (78%)
- When people expressed that they were afraid, they were afraid of the weather, darkness, animals/insects, their roommates and staff



Dignity, Respect, and Rights

- 70% had discussions about their rights in the past year
- 44% would like to vote and had not in the past 5 years
- 88% always had someone to fix problems
- 60% always carried a form of identification





Dignity, Respect and Rights

- 74% reported that support coordinators asked people what they wanted
- 77% said their support coordinator helped them get what they needed
- 76% said they could talk to their support coordinators whenever they wanted

Choice and Control

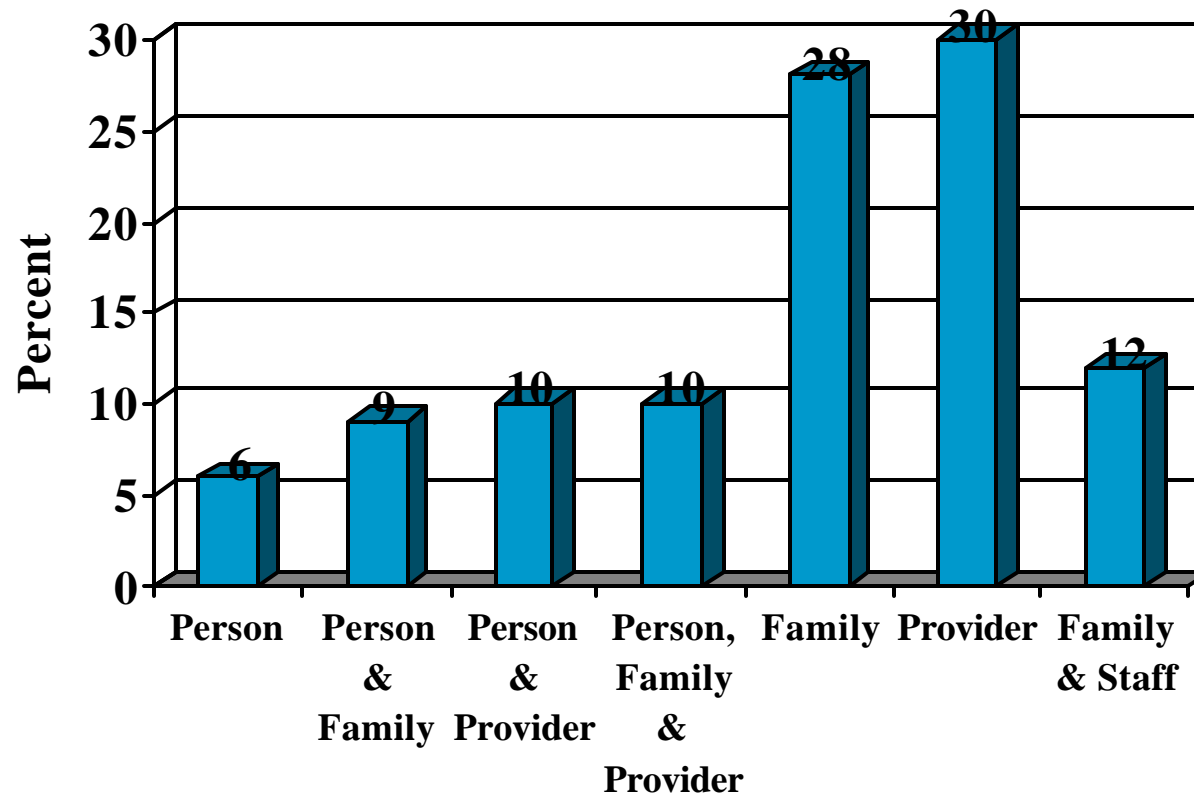
- 30% of people have a key to their home, while 70% do not
- 70% never had their mail read without their permission, so for 16% it happens always



* 39% of the questions in this section were answered by the individual

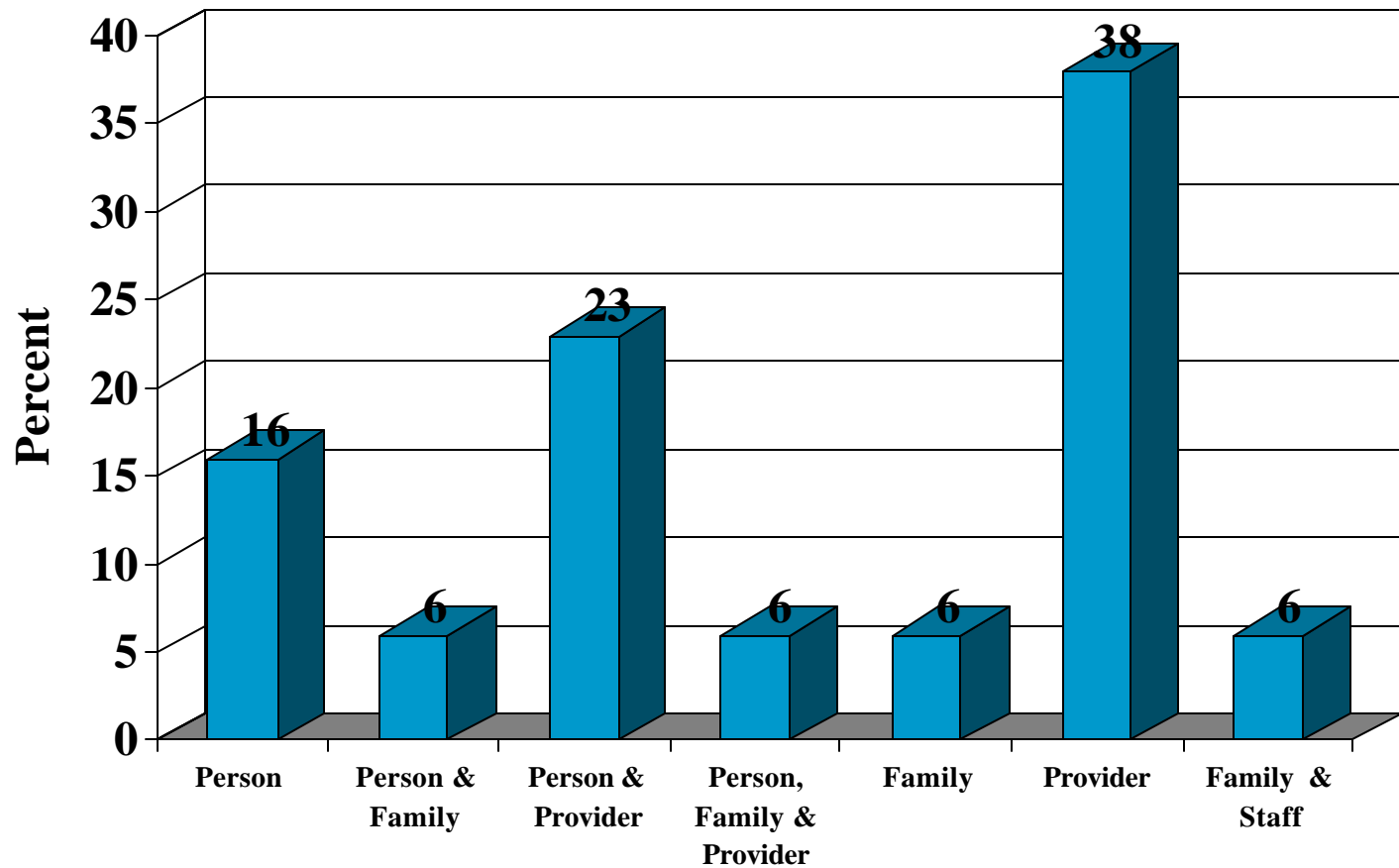
Choice and Control

Who Chose Where the Person Lives?



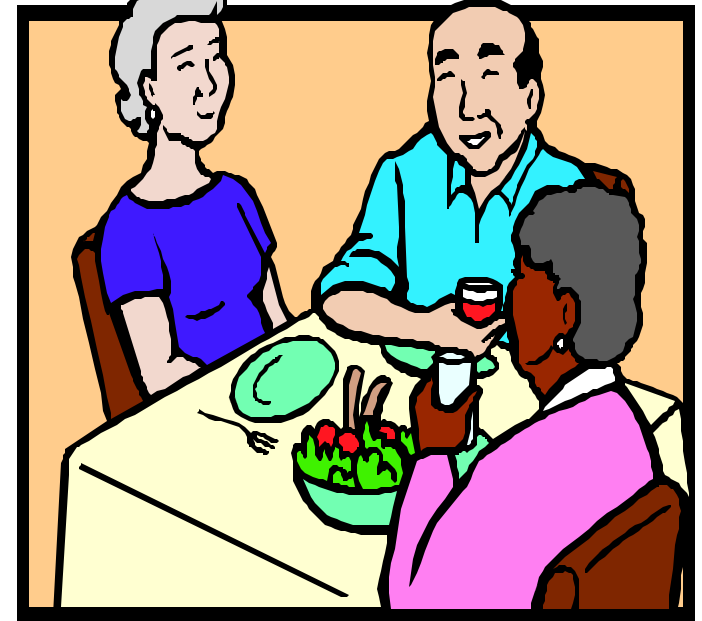
Choice and Control

Who Chose the Person's Day Activity?



Choice and Control

- 71% did not choose any of their housemates
- Most people have their own bedroom (75%)
- Of those who share a bedroom, 64% did not choose with whom they share it





Choice and Control

- 22% of the people chose at least some of their staff at home (alone or with help)
- 27% chose at least some of the staff at work or day activity (alone or with help)
- 7% chose their case manager/support coordinator (alone or with help)



Choice and Control

- 30% said they always choose how much spending money they have each week
- 58% said they always choose what to buy with their spending money



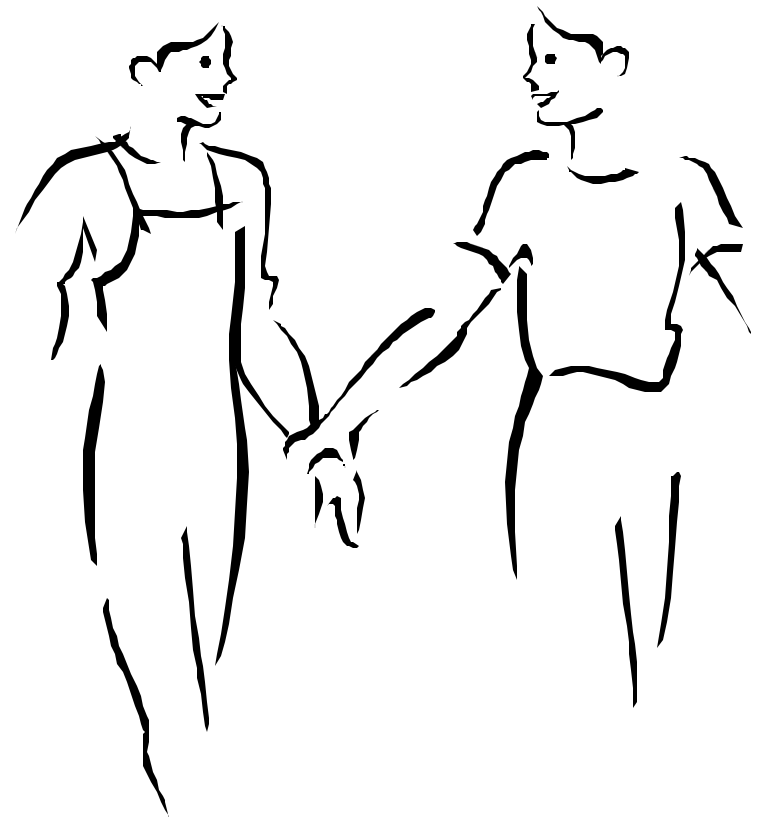
Choice and Control

- Of the 1957 people who do not communicate verbally, only 626 (32%) have a formal communication system in place
- For only half of the people (53%) who have such a system, is it in working order and being used



Relationships

- 83% said they have a best friend
- 83% could always get in touch with family when they wanted to
- 70% could always see friends when they wanted to



* 39% of the questions in this section were answered by the individual



Relationships

- 52% of the people could see, talk to, or visit old friends whenever they wanted
- 67% got a chance to meet new people at least somewhat often



Inclusion

What percent do the following at least weekly?	IM Sample	Harris Poll of People with Disabilities	Harris Poll of People without Disabilities
Socialize	56%	70%	85%
Shop at mall/store	43%	23%	41%
Shop for food	48%	55%	83%
Go out to eat	46%	40%	59%
Go to worship	30%	30%	47%

* 36% of the questions in this section were answered by the individual



Inclusion

- People participated in different community activities
 - Social events (66%)
 - Entertainment (81%)
 - Exercise (43%)
 - Community organizations (40%)
 - Self advocacy group meetings (16%)

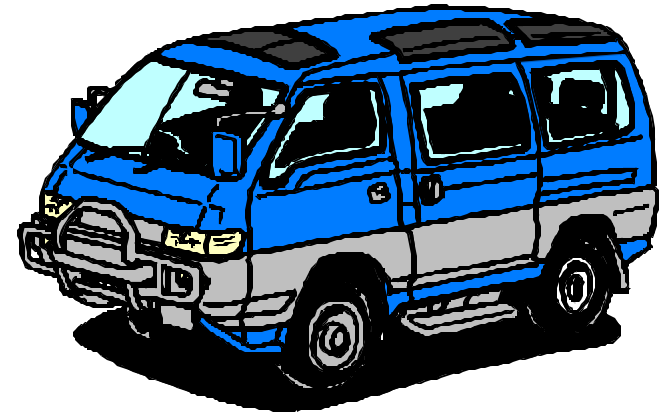


Inclusion

- 21% report they always or most of the time attend community events that are only for people with disabilities
- 7% of people go out alone
- 46% of people go out with just one staff most or all the time

Inclusion

- 90% of the people interviewed said they always have a way to get where they want to go



Equipment and Modifications

- 89% of people report that they have all of the adaptive equipment and home modifications they need
- 88% report that all necessary adaptations have been made to their home



Impressions of the IM4Q Teams

- 87% of the people had staff who interact in ways that give control
- 94% had staff who treat them with dignity and respect
- For 68% of the people, all staff have the skills needed to support them





Impressions of the IM4Q Teams

- 85% say that people seem to have the opportunity to learn new things
- IM4Q teams report that 46% of people have staff that have high or very high expectations for their growth



Homes: Repair and Safety

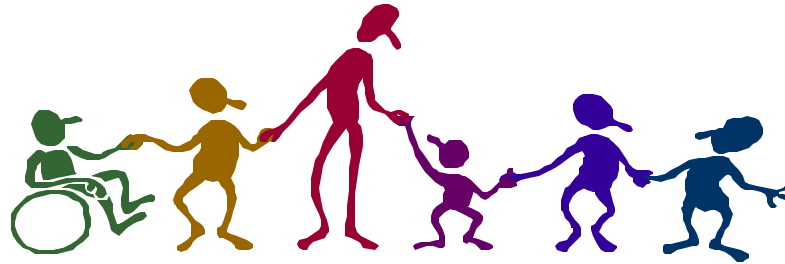
- 93% of individuals live in homes in good outside repair; 91% in good inside repair
- 94% live in homes in safe neighborhoods
- 90% live in homes “fit in” with the neighborhood in which they are located



Personal Belongings

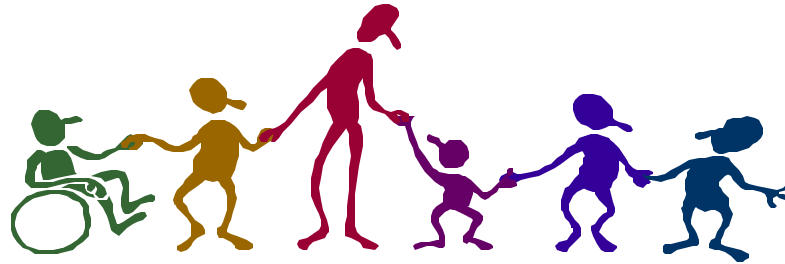
- 95% of people lived in homes that had sufficient space for personal belongings
- 63% lived in homes that reflect the hobbies, interests and personalities of the people who lived there

Family/Friend/Guardian Survey



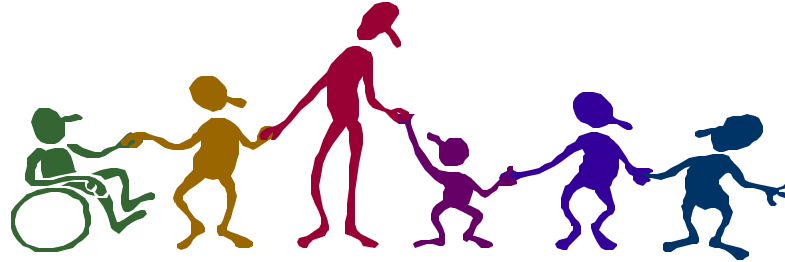
- 2,494 surveys were collected
 - 60% answered by parents
 - 25% answered by siblings
 - 15% answered by others
- Most respondents were satisfied with where their relative lives (92%) and with what they do during the day (87%)

Family/Friend/Guardian Survey



- Most respondents also were satisfied with their relative's staff at home (91%) and with their daytime staff (92%)
- Most respondents believed that their relative is happy at home (89%) and at their work or day activity (86%)

Family/Friend/Guardian Survey



- Staff Communication with their Relative
 - 78% say staff always understand the ways their relative communicates
 - 78% say staff always listen to their relative
 - 79% say staff always respond to their relatives' communication



Pending Issues

- Independence from Counties and System (balancing need for systems change with need for credibility)
- “Closing the Loop” (reconciling local advocacy with a systems change purpose)
- Validity and Reliability
- Cross Disability Perspectives in Monitoring Teams
- Integration with other Monitoring and Licensing Activities
- Quality Context