

annual report 2010

Independent Monitoring for Quality

Every year, thousands of people with disabilities and family members in Pennsylvania are interviewed by Independent Monitoring for Quality (IM4Q) to learn about the overall quality of life for people who receive support through Pennsylvania's Office of Developmental Programs (ODP). The key objective of IM4Q is to provide information that might help improve the quality of life of people with disabilities.

The interviews are conducted in each of Pennsylvania's 48 counties by 38 IM4Q programs throughout the Commonwealth. Each interview team is carefully selected and trained and includes a person with a disability or a family member of a person with a disability. The data are collected and a report is generated for each county program, in addition to the overall statewide summary report.





In 1997, Pennsylvania's Office of Developmental Programs (ODP) created



a Multi-Year Plan delineating its vision, values and goals for the ensuing years. The Plan detailed several recommendations, including one to develop the capacity for independent monitoring in Pennsylvania. The monitoring would help ensure quality of life, services and supports to children ages three and over, and to adults supported by the ODP service system for individuals with intellectual disabilities.

At about this time, the National Association of State Directors of Developmental Disabilities Services, in collaboration with the Human Services Research Institute in Cambridge, Massachusetts established a national project to identify performance indicators to be collected during face-to-face interviews with supported individuals, families supported and providers delivering supports. Pennsylvania joined this project called National Core Indicators, as a pilot state.

IM4Q data have helped to:

• INCREASE consumer voting.

fiscal year 2009-2010

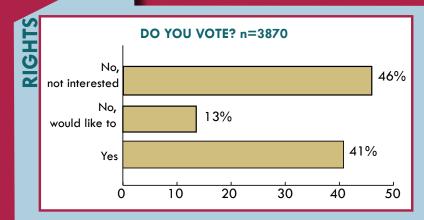
A total of 6621 face-to-face interviews were conducted with people with disabilities. In addition, 2590 interviews were conducted with family, friends and guardians.

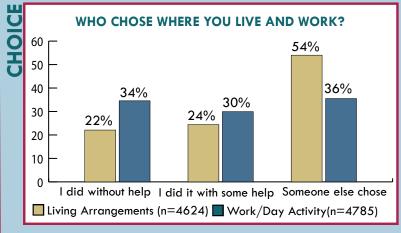
- PROVIDE paid work for people with disabilities as monitors/data entry personnel.
 - ENSURE protection of the privacy of consumer mail.
 - DRIVE development of the ODP Communication Bulletin, leading to improved communication supports.

methodology and a sampling of findings

The Essential Data Elements, the instrument used to conduct the face-to-face interviews, is comprised of the following sections:

- Pre-survey and
 Pre-survey Addendum
 Contact information of interviewee
- Satisfaction
 Satisfaction level with home and support staff
- Dignity, Respect and Rights
 Respect, rights, and fears at home,
 at work, in community
- Choice and Control
 Level of choice and control over lives
- Relationships
 Friends, family, neighbors—
 opportunity to visit and contact them





IM4Q grew from a statewide recognition that individual and family satisfaction, together with other quality measures, are an essential feature of a quality management system. The principles of *Everyday Lives*¹ that were articulated in 1991 as the major drivers of the ODP intellectual disabilities service system required a means to determine whether individuals using services were living in ways that promoted independence, choice and control, relationships and other outcomes and qualities.

¹The fundamental concept of Everyday Lives is that individuals with intellectual disabilities decide, with the support of family and friends how to live their lives and what supports are needed. It also means that individuals are responsible for their decisions and actions.

"If my husband and I should ever disappear one night, I feel sure that IM4Q would be the only mechanism to insure that Robert's quality of life would be assured."

- mother of IM4Q participant

IM4Q participants pictured: 1) Laura enjoys lunch at an annual meeting of The Pennsylvania Training Partnership; 2) Josh and his parents attend a school function; and 3) Robert exercises his right to vote with assistance from his mother.







ACCESS TO COMMUNICATION If the individual does 68% not communicate 32% verbally, is there a formal communication system in place (n=1918)? Yes No SATISFACTION WITH RELATIVE'S HOME 100 AND WORK/DAY ACTIVITY 82% 80 Satisfaction with where relative 60 is living (n=2553) Satisfaction with what relative 40

18%

Somewhat Neutral

11%

Satisfied Satisfied

20

0

Very

does during the day(n=2328)

Somewhat

Dissatisfied Dissatisfied

- InclusionLevel of community inclusion
- Monitor Impressions
 IM4Q team's impression of physical setting, staff support, opportunities for development
- Major Concerns
 Observation of physical danger, sanitation problems, or evidence of abuse or neglect (In the event of imminent danger, teams do not to leave before satisfactory resolution.)
- Family/Friend/
 Guardian Survey
 Family's satisfaction with relative's
 living situation and relative's
 perceived satisfaction (Conducted
 with individual's approval)

selection

Local IM4Q Programs were selected from a variety of organizations—non-service providing chapters of The Arc of Pennsylvania, Consumer Satisfaction Teams (in the mental health system), parent groups, universities and colleges, Centers for Independent Living—and were screened by the Pennsylvania IM4Q Steering Committee. Criteria included: independence of the programs from service delivering entities, consumer and family involvement on governing boards, and involvement of individuals receiving supports and families in data collection activities.

	WEEKLY PARTICIPATION IN COMMUNITY ACTIVITIES			
	activity percentage			
		Harris: People without Disabilities	Harris: People with Disabilities	Independent Monitoring
Z	visit with friends, family and neighbors	85	70	57
2	go to supermarket	83	55	45
3	go to restaurant	59	40	41
3	go to worship	47	30	33
) - 	go to shopping mall or store	41	23	41

Comparison of IM4Q survey results against Harris Interactive, Inc. (commissioned by National Organization on Disability in 2000)

Each local

IM4Q Program
has developed a
process, referred
to as "closing the
loop" which ensures
that follow-up
activity is completed
related to individual
considerations for
improvement.

"I have been with IM4Q for 10 years!... I was excited to think this is finally a project that gives the voice to the consumers and their families, not just another controlled outcome."

- IM4Q staff person









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The IM4Q staff at The Institute on Disabilities at Temple University (pictured left to right clockwise):

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This report is available in alternate formats, upon request.



