
**The Importance of Independent Monitoring for Quality (IM4Q)
for Pennsylvania's Department of Public Welfare (DPW),
Office of Developmental Programs (ODP)**

THE ODP IM4Q PROGRAM

As part of its continuous quality improvement efforts, the Pennsylvania Office of Developmental Programs (ODP) provides funds to all Administrative Entities (AE) to contract with a non-profit entity that does not provide direct service/supports to people with intellectual disabilities. This entity is known as the local Independent Monitoring for Quality (IM4Q) program. The purpose of Independent Monitoring for Quality (IM4Q) is to gather, analyze and report on information in order to improve satisfaction and everyday living outcomes for individuals and families who are registered to receive intellectual disability services through ODP. The focus on everyday living outcomes such as choice and control, inclusion, relationships and rights makes it possible to apply IM4Q or quality practices to individuals wherever they are living and working.

IM4Q requires IM4Q Programs, to conduct face-to-face monitoring interviews with a sample of people receiving services/supports from ODP. With the interviewee's permission, each program also conducts a telephone interview with a family member, friend, or guardian. Based on these interviews, reports are provided to supports coordination organizations (SCOs) within each AE for follow-up action, and data are recorded for system wide quality improvement.

Each local IM4Q program has a governing board which is comprised primarily of people with disabilities and their families. The board hires a coordinator who selects teams of people with disabilities, family members, and interested others to conduct the interviews using the statewide interview instruments.

The IM4Q Program enters data collected through the interviews into the ODP Home and Community Services Information System (HCSIS), along with data collected for the National Core Indicators (NCI) on the person receiving services and their families. With the interviewee's permission, the local IM4Q program submits to the AE a written report with specific considerations to improve the person's life. The AE works with the SCO whose supports coordinators work with a provider agency and/or family/guardian to address considerations. The local IM4Q program is informed of what changes have occurred in a person's life, through the process agreed upon between the AE and the local IM4Q program. The intent of the report is not only to improve the interviewed person's life, but also to assist the AE and provider agency to continuously improve quality. In addition, the IM4Q data are analyzed by ODP's contracted entity, which produces both statewide and individual AE reports. All aggregate reports are public documents.

The Deputy Secretary of the ODP appoints an IM4Q Statewide Steering Committee that independently reviews State reports and makes recommendations to ODP to improve IM4Q practices, policies, operations, supports and services. The Deputy Secretary also assigns IM4Q responsibilities to ODP staff and assigns resources for the operational needs of the IM4Q Program.



THE IMPORTANCE OF IM4Q

1. Consumer, Family, and Citizen Involvement

The IM4Q data from interviews with people receiving at least one ODP service, as well as Family/Friend/Guardian Surveys are important to DPW and ODP because:

- A. Provides a Consumer/Family/Guardian Perspective:** IM4Q, as part of the ODP Quality Management system, is the ONLY INDEPENDENT source of information from families/consumers gathered by ODP allowing consumers, family members, and guardians input about the ODP service system. In 2011-12, 6960 consumers were interviewed and 2500 Family Surveys were collected. Over the 13 years of the program, 78,000 people supported by ODP and close to 30,000 family members have been interviewed.
- B. Employment – Putting People to Work:** Local IM4Q programs employ people with disabilities who otherwise may not have employment. In 2011, 578 people worked in IM4Q, 251 of whom are people with disabilities, 260 are family members of people with disabilities, and 130 are Commonwealth residents interested in disability issues. For many people with disabilities this is their first paid job and the experience has led them to employment outside of IM4Q.
- C. Board Member Participation by Consumers/Families:** IM4Q programs have boards comprised of 51% people with disabilities and family members of people with disabilities. In 2011, 246 people participated in IM4Q Boards, 107 people with disabilities, 102 family members of people with disabilities, and 65 interested Commonwealth residents. People with disabilities and their families have a voice in how ODP and AEs serve/support people.
- D. Monitor Decision-making Participation:** IM4Q monitors (family members/consumers/other non-human service people) record (i.e. write a consideration) what consumers and family members indicate would make their lives better and by doing so are participating in AE and state level partnerships in decision-making.

2. IM4Q Data

- A. Leads to ODP Policy Changes:** The data collected has led ODP to institute policy changes in order to improve its service system and customer satisfaction. For example:
 - Communication – IM4Q data indicated that many people who were interviewed did not have an effective form of communication, which could jeopardize a person's health and well-being. As a result, an ODP Communication Bulletin was developed in which Administrative Entities (AEs) were to emphasize communication training for providers and supports coordinators; supports coordinators were also instructed to regularly review consumer's access/use of technology based on appropriate, clinical assessment.
 - IM4Q data indicated that many people served did not have a valid **form of identification**. ODP issued a memorandum that all people served in the ODP system are required to have identification cards (ID Cards).
 - IM4Q data indicated many people wanting to **vote** were not able to do so. Now supports coordinators regularly ask people if they want to vote and if not registered, they will be provided the necessary assistance to register to vote.
 - IM4Q data indicated that many people served were having their **mail** read without being asked. An ODP memorandum to providers states that a person's **privacy** with regard to receiving mail must be protected.

- Data review provided by people living in **Personal Care Homes (PCHs)** and consequent ODP actions/responses led to stricter reviews and increased oversight of PCHs, more training for PCH providers, and many people moving out of PCH settings into more appropriate residential options.

- B. Supports the Centers for Medicare & Medicaid Services (CMS) Waiver Assurances:** IM4Q is one method that ODP uses to address waiver assurances with regard to health and safety. ODP can use IM4Q data not only to support the minimum requirements, but also to address major quality improvement issues.
- C. Used to Make Data Comparisons:** ODP, by using National Core Indicator (NCI) data, can compare quality of life indicators at the national, state, regional, and county (AE) level with NCI reports issued by the Human Services Research Institute (HSRI), as well as compare data included in IM4Q Statewide Summaries created by the IM4Q technical advisors at the Temple University Institute on Disabilities.
- D. Usefulness for the ODP System:** AE MH/ID Boards, AE Quality Councils and provider agencies are now using IM4Q data to improve their practices, which leads to

better services for people with intellectual disabilities.

- E. Used by Providers for Improvement:** In the same ways that AEs are using IM4Q data to inform their practices, providers now have enough data to analyze and improve their practices with regard to quality improvement efforts for the individuals they support.
- F. Has Longitudinal Usefulness:** The 13+ years of IM4Q data can be used in the ODP Quality Management system as an integral part of improving ODP services. Data can be examined using trend analysis to look for patterns of performance. IM4Q data is an incredibly rich resource for ODP, as well as for other researchers interested in using data collected over a span of years.
- G. A Planning Tool for ODP and AEs:** ODP will use IM4Q to gather information on their business questions to assist with yearly and future planning activities; AEs are required by ODP to use IM4Q data for consideration in their quality management plans and actively use IM4Q data to make change locally. The IM4Q Statewide Steering Committee, an advisory body to ODP, uses the reports developed by HSRI and Temple University's Institute on Disabilities to make policy/practice recommendations to ODP.

IM4Q presentations have been made on the state, national, and international levels, such as the Pennsylvania Advocacy and Resources, Reinventing Quality, the American Association of Intellectual and Developmental Disabilities, TASH (an international [advocacy](#) association of [people with disabilities](#), their family members, other advocates, and people who work in the disability field), the Association of University Centers on Disability, and the Social Role Valorization (Australia) conferences.

3. IM4Q is a Recognized Program of Distinction.

There are published articles, book chapters, and state/national/international conference presentations on IM4Q.

- A. "Independent Monitoring for Quality: Pennsylvania's Experience,"** in **Quality Enhancement in Developmental Disabilities**, Valerie J. Bradley & Madeleine
- H. Kimmich, Paul H. Brookes, MD., Celia Feinstein & Guy Caruso, 2003**
- B. Inter-rater reliability of the Pennsylvania independent monitoring for quality program's**

essential data elements scale, Anthony J. Goreczny, Bree Miller, Brenda Dunmire, Geoffrey J. Tolge; Chatham College, Woodland Road, Pittsburgh, PA 15232, USA, Research in Developmental Disabilities 26 (2005) 231–241

- C. Community involvement and socialization among individuals with ID, Amy L. Kampert, Anthony J. Goreczny; Chatham College, Woodland Road, Pittsburgh, PA 15232, USA, Research in Developmental Disabilities, 28

(2007) 278–286

- D. **Attitudes toward individuals with disabilities:** Results of a recent survey and implications of those results, Anthony J. Goreczny, Erin E. Bender, Guy Caruso, Celia S. Feinstein; Research in Developmental Disabilities 32 (2011) 1596–1609
- E. **Statewide Summaries created by the IM4Q technical advisors at the Temple University Institute on Disabilities**

4. Unique Aspects of IM4Q

- A. **Flexibility and Utility of IM4Q:** The IM4Q process has been used to collect data and evaluate various aspects of the ODP service system. In addition, data on specific subsets have also been collected, e.g., people residing in personal care homes, youth in transition, employment, habilitation, and life-sharing. AEs have been able to add their own pertinent questions to the standardized survey instrument to determine local concerns; they have requested specific reports from their local program for planning purposes as well. Also, some IM4Q Programs create specific reports the AE may want from the IM4Q data for purposes of planning. In FY 2013-2014, IM4Q will incorporate questions from the Supports Coordinators survey, thereby eliminating the need for an additional survey.
- B. **Major Concerns are Discovered and Investigated – Addressing and Preventing Harm:** IM4Q acts as an independent safeguard for ODP by addressing the health and safety of the people interviewed. IM4Q teams report any real or perceived incidents (Major Concerns) jeopardizing the health and

safety of people receiving services, averting potential or additional harm or injury.

- C. **Impact on the Consumer Interviewed:** The people interviewed lives improve as a result of the monitor sharing with the AE written considerations of what would improve a person's life. The AE share the consideration(s) with the Supports Coordination Organization (SCO) who through its supports coordinators shares the consideration with the provider/family to work toward change in the person's life, what is called "closing the loop."
- D. **Significance of Participating in the National Core Indicators (NCI) Project:** Pennsylvania has participated in the National Core Indicators Project since its inception in 1998. 39 states and the District of Columbia currently participate in the project, and the Administration on Intellectual and Developmental Disabilities (AIDD) has placed resources into the Projects of National Significance for more states to begin. The federal government will use this data in benchmarking state practices.

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