

**Pennsylvania  
Office of Developmental Programs (ODP)**

**Independent Monitoring for Quality (IM4Q) Manual**

**January 2016**

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## **Executive Summary**

The purpose of Independent Monitoring for Quality (IM4Q) is to improve the everyday living outcomes for individuals with intellectual disability and their families who are registered to receive services through the Office of Developmental Programs (ODP). IM4Q teams conduct personal interviews with individuals using a standardized survey in order to gather information and produce reports that will enable ODP, Administrative Entities and others to evaluate the effectiveness of services in helping people achieve everyday living outcomes in the areas of choice and control, employment, rights, service planning, community inclusion, relationships and health and safety, and to identify opportunities to improve services. IM4Q is part of National Core Indicators <http://www.nationalcoreindicators.org/>, a national project that involves the use of standard measures across states to assess the outcomes of services provided to individuals and families.

The participation of self-advocates, family members, advocates and citizens from the community as interviewers in the IM4Q activities assures an unbiased and participant-centered approach to evaluating the experience of individuals and the quality of services.

## Introduction

This document is meant to assist each AE and Local Program in establishing the structures, processes, and procedures to operate an effective IM4Q program. This version of the Manual supersedes Pennsylvania's Independent Monitoring for Quality (IM4Q) Protocol and Guidelines, January 2003. The Manual is subject to subsequent written changes and clarifications issued by ODP.

General information describing IM4Q is available on the Department of Human Services website at [Independent Monitoring for Quality](#). For additional information on IM4Q, including updated contact lists of Local Programs, ODP Regional Coordinators, AE Coordinators, and statewide committee members, contact ODP Customer Service at 1-888-565-9435 or [ra-customerservice@pa.gov](mailto:customerservice@pa.gov).

The present document describes the Office of Developmental Program's (ODP) established IM4Q program and is divided into four sections:

Section One, "Program Summary," explains the program, the history, purpose, guiding principles and role in ODP's Quality Framework.

Section Two, "Administrative Roles, Responsibilities and Relationships" describes the required responsibilities of major parties involved in independent monitoring.

Section Three, "IM4Q Operating Practices," provides guidelines that Local IM4Q Programs should consider for the successful operation of their programs.

Section Four, "Appendices," includes a glossary of frequently-used terms and documents that Local IM4Q Programs will need to conduct their work, as well as various flowcharts depicting the structure and processes of IM4Q.

## Section One: Program Summary

### History of Pennsylvania's IM4Q Program

IM4Q grew from a statewide recognition that individual and family satisfaction, together with other quality measures, is an essential feature of a quality management system. The principles of Everyday Lives that were articulated in both the 1991 and 2002 versions as the major drivers of the ODP 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 that came to embody ODP principles. The following points are highlights in the history of IM4Q:

1997 – Office of Mental Retardation (now ODP) Planning Advisory Committee (PAC) issues Multi-year Plan for the Intellectual Disability (ID) system. Recommendation #7 states, “ All county ID programs, or local managing entities, must be required to have in place a local monitoring team that is independent of the local service system and that is made up of a majority of individuals/family members. Outcomes for people and individual/family satisfaction should be the major focus of the assessments.”

1998 – Pennsylvania's Developmental Disabilities Council (PADDC) funds the initial development and training for establishing independent monitoring (IM). The PAC forms an Independent Monitoring for Quality subcommittee, who writes guidelines for the program.

1999 – ODP invites counties to participate in an IM pilot. Twenty counties apply for pilot projects; 13 are awarded for FY1998-1999 and seven begin in FY 1999-2000. Remaining counties are required to begin IM in January, 2000. Technical advisors are contracted to provide technical assistance to all projects. A statewide steering committee is appointed by the Deputy Secretary. Pennsylvania (PA) joins the National Core Indicators (NCI) Project.

2000 – Through a Steering Committee recommendation, Independent Monitoring for Quality (IM4Q) is merged with NCI.

2001 – Data entry into Home and Community Services Information System (HCSIS) is developed.

2013 – Data entry into HSRI's Online Data Entry System Application (ODESA) is instituted.

### Program Description and Purpose

The purpose of PA's IM4Q is to improve satisfaction and everyday living outcomes for the individuals who receive ODP services and their families through the gathering, reporting and analysis of satisfaction and other outcome data. The ODP quality management framework *Everyday Lives: Making it Happen*, issued by the PAC in 2001, principles include:

Choice and Control	Safety
Quality	Individuality
Stability	Freedom
Inclusion	Success
Accountability	Collaboration
Mentoring	Community Integration
Contributing to the Community	Relationships

Local Programs shall be, or shall belong to as a program or subsidiary, a non-profit corporation. Local Programs conduct face-to-face interviews with individuals receiving services through ODP and their families, issue considerations based on these interviews to AEs for follow-up action, and data enter interview results for system wide quality improvement. Each Local Program has a governing board comprised primarily of individuals with disabilities and family members of individuals with disabilities (the non-profit organization's governing board may create an advisory committee to advise it if it is comprised primarily of individuals with disabilities and family members of individuals with disabilities). Each Local Program is independent of the service delivery system administered by ODP, and must be conflict-free (refer to section *Local IM4Q Program Conflict of interest Guidelines*). All Local Programs have a contractual relationship with a single or multiple AEs in PA.

All individuals with an intellectual disability who receive services through the ODP service system and their families are eligible to participate in the IM4Q survey process. With the individual's permission, the Local Program provides written individual considerations for quality improvement to the AE based on the team findings.

Individuals receiving services within the ODP service system are interviewed by a trained monitoring team assigned by the Local Program Coordinator. Each team must include an individual with a disability or a family member. The monitoring team conducts an interview with the individual receiving services by obtaining responses to questions on a standardized survey instrument, either the Essential Data Elements (EDE), the NCI Adult Consumer Survey, or a specific pilot survey. The monitoring team also makes its own observations based on the visit that may include additional discussion with the individual receiving services. An additional survey, the IM4Q Family/Friend/Guardian Survey (F/F/G Survey), will be completed at this time with family, friends, and guardians, although this is usually done in a separate in-person or telephone survey. All recorded responses to the survey questions and monitoring team observations are data entered into a secure web-based information system, called ODESA (Online Data Entry System Application), by the Local Program. External evaluation of Local Programs is emphasized in order to continually improve the quality of the programs. ODP provides specific instructions for each Local Program to conduct an external evaluation on a regular basis. Also, the IM4Q Technical Advisors perform evaluations through program review visits with a number of Local Programs each year.

### **Guiding Principles for IM4Q**

This ODP quality improvement program has five guiding principles to which all parties involved in IM4Q must adhere. These principles distinguish IM4Q from other ODP quality management initiatives and act as safeguards to keep IM4Q on task with its mission.

#### **1. Independence of the Program**

Under the contract established with the AE, the Local Program's governing board will insure that the program functions independently of the AE.

#### **2. Insurance against Conflicts of Interest**

Each Local Program will guard against any conflicts of interest in its governance structure, decision to operate any new programs, board membership, selection, and assignment of team members.

### **3. Local AE Integration**

Each Local Program must be integrated within its local area, developing any necessary processes and procedures that are unique to the AE(s) in which it operates. Although the Local Program is part of a larger ODP statewide continuous quality improvement effort, each Local Program should maintain its local identity while adhering to statewide protocols and practices, which are discussed in Section Two: “Administrative Roles, Responsibilities and Relationships.”

### **4. Spirit of Continual Learning**

All parties involved in IM4Q must learn together how best to meet the program’s purpose. Therefore, a spirit of cooperation and flexibility is necessary for IM4Q to keep growing in effectiveness.

### **5. Confidentiality and Consent**

The Institute on Disabilities at Temple University engaged in a formal review process in accordance with the policy of the Department of Health and Human Services on protection of human subjects in research. The project, entitled Independent Monitoring for Quality, was reviewed by Temple University’s Institutional Review Board (IRB) and approved on November 15, 2002. This approval is in respect of the rights and welfare of the subjects involved; appropriateness and adequacy of the methods used to obtain informed consent; and risks to the individual and potential benefits of the project.

All parties involved in IM4Q want to ensure that the people to be interviewed have given their consent for the interview. The permission to be interviewed is to be obtained by the Local Program and not the AE and/or supports coordinators. This applies to individuals who have a legal guardian as well. The Local Program provides a number of opportunities for the person identified to be interviewed to indicate whether he/she wishes to be interviewed. Such opportunities occur at the initial contact with the person or his/her legal guardian to arrange for an interview; before actually starting the interview through a statement read to the prospective interviewee in the interviewing instrument; and by the interviewee having the ability to terminate the interview at any time during the interview process.

The confidentiality of the person being interviewed is of the highest priority to the Local Program. Each Local Program team member signs a confidentiality statement before ever conducting an interview. These are available to be reviewed by the person being interviewed and/or his/her guardian. Also, team members/monitors are instructed during their annual orientation and training about the importance of confidentiality. In addition, ODP has developed very clear expectations and protocols regarding confidentiality when the Local Program enters data into the web-based data entry systems.

Procedures and safeguards established in IM4Q have also been reviewed by ODP against the Health Insurance Portability and Accountability Act (HIPAA) of 1996. HIPAA requires the protection and restriction of protected health information (PHI). PHI is information that identifies an individual or “there is reasonable basis to believe” could be used to identify an individual. Reference the U.S. Department of Health and Human

Services (HHS) published final regulations, entitled Standards for Privacy of Individually Identifiable Health Information 45 CFR Parts 160 and 164.

### **Benefits of IM4Q**

IM4Q is unique in that those interviewing the people receiving supports and services are people with disabilities, family members of people with disabilities, and interested others, all of whom are independent. This independent program is of great assistance to ODP by:

#### **1. Promoting Continuous Quality Improvement:**

The program strives, through cooperation and shared responsibility, to improve the quality of services and supports provided to persons with intellectual disabilities. It will support the principles of Everyday Lives and self-determination throughout the system.

#### **2. Gathering Independent Information About Lives of People Served/Supported:**

On a yearly basis, monitoring teams will interview a sample of individuals (children and adults) who are registered within an AE and who receive services/supports. In the event that people want their information to remain confidential, it will be done.

#### **3. Acting as a Safeguard Regarding “Major Concerns” for the People Served/Supported:**

If monitoring teams have any major concerns about abuse, neglect, and/or safety during an interview, they will report their concerns immediately to the appropriate parties. The team will also take safety measures if they perceive any imminent threat of danger according to the policy established by each AE and Local Program.

#### **4. Identifying Provider/System Promising Practices:**

ODP, Technical Advisors, and Local Programs will identify “Promising Practices” (e.g., as described in the Everyday Lives document) in providing services and supports to people, and share these with the AE.

#### **5. Identifying Considerations for Change:**

If a person indicates during their interview that they would like to affect a change in their life, the IM4Q program team will help the participant identify the possible avenues available to achieve that outcome. With the participant’s agreement, the suggested change (referred to as a consideration) will be presented to the Supports Coordinator and AE, which, in turn, will forward to the appropriate providers and members of the individual’s support team, and then activities will be completed to attain that outcome. This process is called “closing the loop”. Family members, guardians, support persons (e.g. staff), or monitors may also make suggestions for a consideration. AEs, Supports Coordinators (SCs), and the Local Programs collaborate to effect change for a person based on these considerations.

## **6. Interviewing Families/Friends/Guardians about Service/Support Satisfaction:**

With the person's consent, a family member, friend, or guardian will be interviewed (typically by mail or telephone) regarding their perception of services/supports.

## **7. Collecting and Analyzing Consistent Data Sources:**

Each Local Program must use the ODP's required instrument to conduct interviews. Only in this way can it be assured that the data collected across Local Programs is consistent for comparison. In addition, Local Programs are required to use any other tools, surveys, or forms identified by ODP. Local Programs will enter all data collected into ODESA. The Human Services Research Institute (HSRI) will analyze Pennsylvania's National Core Indicators data and publish their findings. An independent contracted entity of ODP will analyze data generated by IM4Q.

## **8. Developing and Disseminating Reports:**

The external reports generated from the National Core Indicators analysis will be issued to ODP by HSRI for appropriate action, such as inclusion in the quality management plan or to assist ODP in developing systemic change. These reports are posted to HSRI's website ([www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)). An entity contracted to ODP will analyze the other state-generated (i.e. non-Core Indicator) data and provide data/reports as requested to ODP. The statewide data reports will be disseminated to the public.

The Statewide Steering Committee will review and analyze the statewide summary reports, and make recommendations for policy and system change to ODP. The reports' focus will be about life outcomes and satisfaction of people served by Pennsylvania's intellectual disability system.

The contracted entity will also develop individual AE reports from the non-core indicator data. These reports are issued to each AE and their respective Local Programs. These reports will be made public as well. The Statewide Steering Committee may also advise ODP to do other reports based on collected data. Reports will provide information to people receiving services, their families, and the public to enable them to influence system change and make informed choices about services.

## **9. Promoting Collaborative System Change:**

ODP, AEs, and providers will use the reports and Statewide Steering Committee recommendations to evaluate potential system changes and improve service quality. People receiving services/supports and their families will be part of the process of change.

### **IM4Q in the ODP Quality Framework**

IM4Q is part of the ODP Quality Management (QM) Strategy that includes initiatives designed to ensure health and well-being and to improve the quality of services available to individuals with intellectual disabilities and their families. The QM Strategy is based on the mission of ODP to support Pennsylvanians with intellectual disabilities to achieve greater independence, choice, and opportunity in their lives. The Strategy is to continue refining a system of quality services and supports delivered in respectful, inclusive environments; to foster competent, evidence-

based practice, and to extend ODP's reach to all Pennsylvanians with intellectual disabilities who need services.

This ODP Quality Management Strategy is guided by values and principles expressed in *Everyday Lives, Making it Happen*, issued by the PAC in 2001. The ODP QM framework Bulletin (## 00-10-02) can be reviewed on the DHS website at <http://www.dhs.state.pa.us/publications/bulletinsearch/bulletinselected/index.htm?bn=00-10-02&o=N&po=ODP&id=03/22/2010>.

Beginning with structures and processes that assure compliance with minimum standards, the quality management framework:

- Maximizes trust, collaboration, and accountability among all parts of the system;
- Promotes continuous quality improvement;
- Furthers the adoption of promising practices; and
- Is responsive to customer feedback and informed by data, the Quality Management system measures, addresses, and enhances quality of life, services and supports, and organizational practices.

The objectives of the Quality Management Framework are to:

- Identify outcome areas from *Everyday Lives*;
- Analyze and evaluate system performance;
- Disseminate information;
- Identify practices that need to be adopted, modified or eliminated;
- Implement training;
- Recommend policies and procedures;
- Identify processes that must/need to be supported, or modified, or created; and
- Involve as many people as possible.

## **Section Two: Administrative Roles, Responsibilities, and Relationships**

### **IM4Q Organizational Structure and Processes**

In order to more fully understand the organizational structure and processes of IM4Q that are described in this section, flowcharts with brief narratives for each are offered in Appendix B: IM4Q Program Structure and Processes. In no way should these become a substitute for the text in the body of this document.

#### **Local Programs**

Each Local Program is selected by the AE, based on ODP criteria, and approved by ODP with the recommendation of the Statewide Steering Committee. Each Local Program is a non-profit corporation, or a program of a non-profit corporation, that does not provide ODP funded direct services to individuals with intellectual disabilities (Refer to *Program Independence and Conflict of Interest* section of Manual). Each Local Program is managed by a Program Coordinator. The non-profit corporation's board of directors shall ensure proper oversight of the Local Program, and shall supervise the Program Coordinator or appropriately delegate supervision responsibilities to staff that are in the chain of command to the board of directors, and shall ensure that IM4Q principles and practices are safeguarded. The following are required activities of each Local Program:

- Arrange interviews with individuals receiving services and their families and determine whether the individual receiving services chooses to be interviewed;
- Collect outcome and satisfaction data from individuals receiving services and their families using standard survey instruments and protocols established by ODP;
- Offer considerations for improving the participant's life, enter considerations in HCSIS and through HCSIS obtain confirmation regarding how these considerations are addressed by the AE, and follow up as necessary to ensure that considerations are resolved to the satisfaction of the individual receiving services or family;
- Data enter all survey results in the ODESA in a timely and accurate manner in accordance with ODP-established timeframes;
- Identify patterns and trends that can promote quality improvement on a provider and AE level;
- Work with AE and provider networks to orient and update stakeholders on IM4Q practices, findings, and related information;
- Negotiate terms and conditions of its IM4Q contract with AE/County Program in consultation with and final approval of its board and agency director, when the Local Program is part of a larger agency;
- Establish Major Concerns and Closing the Loop policies in collaboration with the AE that are reviewed yearly with the AE.
- Operates an office with adequate space and security for the Local Program to operate in an effective and efficient manner; and
- Ensures that recruitment and retention of IM4Q board and monitors represent the diverse set of communities and service recipients visited by monitoring teams.

#### **Local Governing Board or Advisory Committee Requirements**

Each Local Program shall have a governing board or an advisory committee comprised primarily of individuals with disabilities and family members of individuals with disabilities.

Because non-profit corporations must have a governing board of directors, the board of directors of the non-profit corporation to which the Local Program belongs may also serve as the advisory committee if it is comprised primarily of individuals with disabilities and family members of individuals with disabilities. The governing board or advisory committee shall have local membership and by-laws.

The majority of the governing board or advisory committee (51%) is expected to consist of individuals with disabilities and family members of individuals with disabilities. Governing boards or advisory committees are encouraged to include individuals who communicate in alternative ways or family members of individuals who rely on an alternative communication device or method. All governing board or advisory committee meetings are structured to ensure maximum participation of its members.

The governing board or advisory committee will meet at least three times a year and applies generally-accepted meeting protocols, including minutes of each meeting and voting by a quorum of board members to arrive at decisions and the establishment of committees.

Individuals with intellectual disabilities and family members, including individuals who receive services, can serve on the governing board or advisory committee and be paid monitors when appropriate steps are taken by the board/committee to remove the individual from decisions that might be a potential conflict of interest, including decisions on payment of the monitors.

With the advice and consent of the governing board or advisory committee, the Local Program will ensure that the following activities are completed:

- Develop procedures/policies for the operation of the Local IM4Q Program in accordance with the IM4Q Manual and in collaboration with the AE;
- Develop a direct relationship with the AE MH/ID Advisory Board, which has a statutory obligation to review and evaluate services;
- Review the various IM4Q reports and provide recommendations to the AE for improving the quality of supports and services.
- Participate in a regular external evaluation of the Local Program;
- Insure that the Local Program Coordinator is hired, supervised, and evaluated on an ongoing basis.
- Sign all contracts with the AE;
- Determine policies for criminal clearances;
- Determine policies for mandated reporting; and
- Make needed changes to ensure a successful Local Program and fulfill any obligations specified by ODP

### **Local Program Coordinator**

The Program Coordinator is responsible for the development and ongoing operations of the Local Program in accordance with the Manual. The Program Coordinator:

- Ensures that monitoring team members are recruited, oriented, trained, supervised, paid, and supported to conduct IM4Q responsibilities in an effective and efficient manner. See Section Three: IM4Q Operating Practices for additional information about monitoring teams under the heading of Monitoring Team Practices;

- Ensures that each monitoring team conducts its survey work in accordance with IM4Q standards and timelines, including participation of individuals with disabilities and their families on monitoring teams;
- Ensures that IM4Q interviews with individuals receiving services and their families are conducted in accordance with sampling criteria and interview protocols approved by ODP;
- Ensures that incidents of suspected abuse and neglect of individuals receiving services (i.e., Major Concerns) are reported to the appropriate agencies;
- Ensures that the Older Adults Protective Services Act (OAPSA) (35 P.S. Chapter 10225.101-10225.708), Child Protective Services Law (CPSL) (23 PAC. S Chapter 63, and the Adult Protective Services Act of 2010 (APS) (35 P.S. §§ 10210.101) are followed accordingly;
- Develops standard practices for addressing Local Program considerations with each AE in a timely and effective manner;
- Conducts follow-up after monitoring to ensure that considerations have been addressed;
- Ensures accurate data is obtained from IM4Q interviews in accordance with ODP IM4Q confidentiality and security requirements, as well as applicable state and federal standards, including HIPAA;
- Meets with and provides reports to the AE, AE MH/ID Advisory Board, Supports Coordination Organizations (SCO) within the AE, and providers of service on IM4Q findings and recommendations, including summary reports as may be required for quality improvement purposes by an AE Quality Management Council;
- Incorporates independent and external evaluation measures into a quality management plan for the Local Program that is implemented in a timely manner;
- Attends and assigns personnel and monitoring team members to attend regional meetings, the Annual Statewide Training, and other trainings and orientations provided by ODP for Local Programs;
- Participates in and provides the necessary information for a program review requested by the IM4Q Technical Advisor and Regional ODP IM4Q personnel which the Local Program and AE IM4Q Coordinator attend;
- Completes statistical reports required by ODP in a timely fashion, including the Annual Statistical Report, and cooperates with ODP and its technical advisors in quality improvement activities stemming from these reports;
- Reviews and incorporates information from communications issued by ODP into Local Program operations in a timely and effective manner;
- Contacts their ODP Regional Coordinator when there are questions and comments with IM4Q Announcements, instructions, protocols, and guidelines that cannot be addressed on a local or AE level;
- Establishes and maintains ongoing relationships with AE personnel, the AE MH/ID Advisory Board, SCOs, and providers of service to promote quality improvement in the IM4Q program; and
- Works with the IM4Q Lead at each State Center to plan, conduct and follow-up on IM4Q reviews when appropriate.

Although the Local Program is a contracted entity of the AE; direct and ongoing communications between the Local Program, ODP, and the Technical Advisors is encouraged due to the independent monitoring nature of the program. The Local Program Coordinator is authorized to directly contact the ODP Regional Coordinator or IM4Q Technical Advisor when encountering any questions or concerns regarding operational standards, data entry, sampling, training, or technical assistance to find a resolution, but is encouraged to work first with the AE. The ODP

Regional Coordinators will ensure that identified issues are reviewed with the Technical Advisors, AEs, other Regional Coordinators, and the Central Office ODP Coordinators.

The Local Program Coordinator, in consultation with their IM4Q governing board, is also encouraged to directly contact other public agencies such as the Disability Rights Network (800-692-7443), when the Local Program determines that the AE and ODP have not addressed health and welfare issues stemming from an IM4Q interview, or that considerations are not being addressed to the satisfaction of the individual receiving services and his/her family. The Local Program Coordinator or designee is also encouraged to directly contact:

- The DHS HCSIS Help-Desk (866-444-1264) for obtaining HCSIS user rights and instructions for IM4Q purposes;
- IM4Q Technical Advisors for information related to program evaluation or using IM4Q results in reports and analysis; and
- IM4Q Management and Statewide Steering Committee representatives to recommend changes and improvement in statewide IM4Q operations, policies, and practices.

### **IM4Q Monitors**

IM4Q monitors are individuals with disabilities, family members of individuals with disabilities, and other interested adults, including students, who are at least 18 years of age. Monitors are assigned to a team by the Local Program Coordinator to conduct an interview using an ODP-approved survey tool. Each monitoring team must include at least one person with a disability or a family member. For more information on team member selection, recruitment, as well as team formation and expectations, please refer to Section Three: IM4Q Operating Practices, under IM4Q Team Practices.

### **Administrative Entities (AEs)**

The PA Department of Human Services has established AEs as designees of ODP to authorize services funded through the Home and Community Based Services (HCBS) Waivers for individuals with intellectual disabilities. IM4Q responsibilities of AEs are established pursuant to a written agreement between AEs and ODP. Each AE is responsible to:

- Select and enter into a yearly contract with a Local Program to conduct independent monitoring
- Assign AE IM4Q Coordinator responsibilities to one of its staff;
- Ensure that there is a written policy developed with the Local Program for addressing IM4Q considerations, closing the loop, major concerns, and any other policies determined by ODP that align with ODP requirements;
- Ensure that SCOs and other providers of service cooperate in providing needed IM4Q information and addressing IM4Q considerations in a timely fashion;
- Ensure that IM4Q reports related to services in their counties are shared with individuals receiving services, families, providers of services, quality councils, and the AE MH/ID Advisory Board;
- Ensure that individuals receiving services and their families are advised about IM4Q during registration into the AE for services;
- Ensure that Local Programs are paid in a timely manner based on documentation that surveys are finalized based on ODP requirements;
- Ensure that AE-level IM4Q data are used to improve services and supports through the AE's Quality Framework; and

- Contact ODP or the Technical Advisors when technical assistance is needed to analyze reports or utilize considerations and findings within the AE's Quality Framework.

### **AE IM4Q Coordinator**

Each AE is responsible for the assignment of a staff person, referred to as the AE IM4Q Coordinator, to provide administrative support related to IM4Q for that AE. When a personnel change occurs, the AE is responsible to provide ODP, Technical Advisors, and the Local Program with updated contact information.

The AE IM4Q Coordinator is responsible for:

- Establishing with the Local Program a standard written process, referred to as Closing the Loop (CTL), for addressing Local Program considerations and ensuring that this process is followed by providers, SCOs and other AE personnel;
- Reviewing annual IM4Q sample subsets provided by ODP to ensure that only individuals eligible for survey interviews are included and ensuring that the information is correct and complete for IM4Q and NCI pre-survey information;
- Ensuring that Local Programs have information they need to schedule and conduct monitoring visits;
- Addressing major concerns for an individual's health and safety in accordance with incident reporting requirements of ODP;
- Reviewing allegations of abuse and neglect and addressing them in accordance with the Older Adults Protective Services Act (OAPSA) (35 P.S. Chapter 10225.101-10225.708), Child Protective Services Law (CPSL) (23 PAC. S Chapter 63, and the Adult Protective Services Act of 2010 (APS) (35 P.S. §§ 10210.101);
- Ensuring that IM4Q reports and findings are disseminated and/or accessible to the appropriate providers of service and other agencies within the service system, including individuals receiving services and their families;
- Ensuring the IM4Q reports and findings are shared with and utilized within the AE quality management process as required by ODP;
- Sharing information provided through IM4Q communications, including information related to the maintenance and operation of IM4Q in HCSIS;
- Attending regional meetings, the Annual Statewide Training, other trainings and orientations provided by ODP, and IM4Q Local Program Reviews;
- Approving the dissemination of information materials at IM4Q interviews with individuals receiving services and their families; and
- Reporting to ODP issues that are in conflict with this Manual (e.g. conflict of interest).

### **IM4Q Program Contract and Funding**

Each AE is responsible to select and contract with an organization that meets the qualifications of a Local Program as established in this Manual. The AE's contract with the Local Program will comply with the regulations set forth by ODP. The contract will include: program description of services to be provided, conflict of interest statement to maintain IM4Q's independence, method of payment for services delivered, and any special requirements of contractual relationship between the two parties.

All IM4Q funding allocated by ODP to the AE is for the operation of the Local Program and is not available for any other purpose, including administrative support provided by AE personnel and supports coordination organizations.

IM4Q funding is allocated on the basis of the Local Program's performance in the collection, entry, and finalization of surveys. The number and type of surveys to be finalized is specified in the AE Sample Allocation. The AE is responsible to ensure that payment to the Local Program corresponds to the number of finalized surveys it provides, but not to exceed the amount of the allocation.

All Cost of Living Adjustments (COLAs) allocated to the AE for the Local Program must be paid directly to the Local Program unless otherwise specified in writing by ODP. The COLA shall be paid in a timely fashion.

### **AE State Center Contracts**

State Centers arrange for IM4Q surveys through a governmental contract with AEs, including the per-survey rate. All agreements are for one year with extensions, as permitted by the Department of Human Services. The AE receives payment from the state center, outside the Sample Allocation, for surveys completed with individuals living in the state centers. The AE, in turn, reimburses the Local Program for the finalized surveys.

### **AE Quality Management Plan**

Each AE is responsible to have a written quality management strategy as defined in the AE Operating Agreement as, "Quality Management (QM) Strategy – The structure, process, roles, responsibilities, and methods the Department uses to manage its performance to achieve quality results including continuous cycles of performance measurement (discovery), correction of individual problems (remediation), and implementation of system-wide change as needed (improvement)." As part of this quality management strategy, the AE is responsible to have an annual written quality implementation and improvement plan that includes IM4Q as part of the measurable indicators assigned by ODP. Each AE is expected to consider the following reports in development of the quality implementation and improvement plan:

- The annual IM4Q Summary for the AE issued by the contracted entity, and
- Any other IM4Q reports affecting services and supports to individuals served by the AE and issued by ODP or the contracted entity.

If the AE has a quality management committee, it should consider inviting the Local IM4Q Program Coordinator to be a member of such committee.

### **The County MH/ID Advisory Board**

Among its other duties, the County MH/ID Advisory Board is established under the MH/ID Act of 1966 to review and evaluate needs and services, to develop annual plans, and to make recommendations to the AE. In IM4Q, the role of the County MH/ID Advisory Board is to allow and encourage the Local Program to be independent and self-governing. With regard to its interface with the Local Program, the County MH/ID Advisory Board is expected to utilize IM4Q as part of its evaluation, planning and recommendation functions.

Recommended County MH/ID Advisory Board functions related to IM4Q include:

- Review of annual IM4Q Statewide and AE Summary Reports provided by the contracted entity;
- Periodic meetings with the AE IM4Q Coordinator and/or board to review and evaluate needs and services based on the Local Program findings and recommendations;
- Utilization of IM4Q findings and recommendations in the development and justification of annual plans issued by the County MH/ID Advisory Board; and
- Utilization of IM4Q findings in the development of recommendations to the AE to improve services and the operation of the AE Quality Framework.

### **Supports Coordinators**

Supports Coordinators (SCs) are responsible to locate, coordinate, and monitor services of individuals receiving services through the ODP service system.

All coordination functions for IM4Q that are assigned to the SC are eligible for Federal Financial Participation (FFP) in accordance with the approved current HCBS Waiver. The time and resources of SCs in fulfilling IM4Q responsibilities assigned by the AE, including completion of pre-survey information and following up on IM4Q considerations, constitute an allowable coordination of services subject to FFP for individuals receiving Medicaid HCBS Waiver services. Supports Coordination functions provided through base funds for individuals not enrolled in the waiver are also eligible service costs.

The following functions related to IM4Q are generally the responsibility of the individual's SC, although the AE can delegate some of these functions to other administrative staff or to other provider agencies. The SC, or other AE designee, is authorized to ensure that:

- IM4Q is explained to individuals and families and that they are encouraged to participate in the IM4Q process;
- The Local Program has the information it needs about an individual selected in a HCSIS-drawn sample to complete pre-surveys relating to demographic and service information available in HCSIS and other sources;
- IM4Q demographic data are entered and updated in HCSIS;
- Ensure that IM4Q considerations are addressed as part of the Closing the Loop process;
- IM4Q considerations requiring a change in services or supports are reviewed as part of the ISP process. IM4Q considerations addressed by the ISP team are documented in the ISP as appropriate; and
- Attend trainings pertaining to IM4Q.

SCs can contact their AE IM4Q Coordinator for additional information about IM4Q. SCOs are also encouraged to meet regularly with their Local Program to ensure that roles and responsibilities concerning the Closing the Loop process are fulfilled.

### **Central Office, Regional Office, and State Center Coordinator and Leads (ODP)**

ODP Central Office and its four Regional Offices (Central, Northeast, Southeast and Western) have professional staff assigned to manage the IM4Q operations in collaboration with the Technical Advisors, the Statewide Steering Committee and the Management Committee. ODP Regional Office and State Center Leads have direct contact with Local Program Coordinators and AE Coordinators.

ODP Central Office IM4Q Coordinators are responsible to:

- Manage IM4Q within the ODP Quality Framework;
- Establish and participate in managing statewide priorities for quality improvement based on Statewide Steering Committee recommendations;
- Work with DHS contractors to maintain HCSIS and other IM4Q functions;
- Work with the Human Services Research Institute (HSRI) to maintain ODESA functions;
- Issue reports on IM4Q data for quality improvement purposes in collaboration with Technical Advisors;
- Maintain ongoing contact with Technical Advisors on reports, training, and technical assistance and other assignments;
- Establish statewide protocols, policies, and practices with the advice of the Management and Statewide Steering Committees and Technical Advisors;
- Meet with Statewide Committees, workgroups, AEs, and Local Programs regularly;
- Provide technical assistance and address concerns of Local Programs and AEs;
- Issue regular communications to clarify IM4Q operations, policy and protocol (e.g., the IM4Q Announcement);
- Ensure statewide compliance with state and federal requirements; and
- Sponsor and conduct training for Local Program staff/monitors/board members, AEs, Supports Coordinators, and Management and Statewide Steering Committee members through meetings, conferences, and information-sharing opportunities in collaboration with the Technical Advisors; and
- Attend the IM4Q Management and Statewide Steering Committee meetings.

ODP Regional Office IM4Q Coordinators are responsible to:

- Review IM4Q samples and issue to the appropriate AEs;
- Facilitate regional IM4Q meetings;
- Periodically review whether the AE is meeting its IM4Q responsibilities as specified in the AE Operating Agreement;
- Maintain ongoing contact with Technical Advisors on reports, training and technical assistance, and participate in program reviews and work on issues such as contractual issues, etc.;
- Participate in Management Committee meetings and workgroups;
- Meet with AEs and Local Programs on a regular basis;
- Provide technical assistance and address concerns of Local Programs and AEs; and
- Sponsor and conduct training for Local Program staff/monitors/board members, AEs, and Supports Coordinators through meetings, conferences, and information-sharing opportunities.

State Center IM4Q Coordinator will be appointed by ODP and is responsible to:

- Work with the five State Center Leads insuring the State Center IM4Q program runs according to State Center IM4Q protocol and policies;
- Ensure that considerations are addressed and data is used for each center's quality management plan;
- Ensure that the five centers are meeting and developing quality management strategies; and
- Attend the Management and Statewide Steering Committee meetings.

State Center IM4Q Leads are responsible to:

- Review sample received by the Local Program;

- Coordinate interviews;
- Address considerations including communication with Local Programs and AEs;
- Attend the regional meetings and annual statewide training; and
- Implement Quality Improvement based on the Annual State Center Report.

### **Technical Advisors**

ODP contracts for the provision of technical assistance through the contracted entity. The contracted entity provides individuals with expertise in conducting IM4Q through survey development, sampling, data analysis, report writing and technical assistance expertise. The providers of technical assistance are referred to as Technical Advisors.

The key functions of the Technical Advisors are to:

- Issue reports, data extracts, and analysis of the data, including annual statewide summaries, AE summaries, and state center and pilot subset reports;
- Provide technical assistance to ODP, Local Programs and AE Coordinators;
- Develop and edit survey tools in consultation with the ODP, Local Program Coordinators, and AE Coordinators;
- Participate on the Statewide Steering Committee, Management Committee, subcommittees and workgroups;
- Organize and provide training as necessary on the survey tools and team interview protocols;
- Consult regularly with ODP on IM4Q and quality management functionalities;
- Consult with Local Programs, AEs, and ODP in utilizing IM4Q results for quality improvement;
- Review external evaluations of Local Programs for quality improvement purposes;
- Organize the Annual Statewide Training;
- Conduct program reviews of Local Programs to ensure programs are functioning effectively and in accordance with ODP requirements;
- Ensure corrective action plans are completed when necessary as a result of Local Program reviews;
- Assist with the external evaluation of the entire IM4Q Program;
- Act as a liaison with National Core Indicators as appropriate.

### **IM4Q Statewide Steering Committee**

The Statewide Steering Committee began in 1999 as the State advisory board for Independent Monitoring for Quality. The role of the Statewide Steering Committee is to uphold the purpose and the guiding principles of IM4Q. The committee advises and reports directly to the Deputy Secretary of ODP and makes recommendations to improve IM4Q operations, outcomes, and connections to the Quality Framework. The committee has no operational responsibility to county government or to providers of service.

The Statewide Steering Committee will be comprised of members as follows:

Voting Members:

- AE/County Program MH/ID Board Member;
- Arc of Pennsylvania Parent Representative;
- Five Self-Advocates who may have experience as monitors on local program teams;

- Five Family Members who may have experience as monitors on local program teams
- State Center/Pennsylvania League representative, and;

Non-Voting Members:

- Pennsylvania Developmental Disabilities Council representative;
- Disability Rights Network representative;
- University Center for Excellence at Temple University representative;
- Administrative Entity representative;
- Provider Association Representative;
- Supports Coordinator or SC Supervisor; and

Non-Voting Staff members:

- ODP
- Technical Advisors

All members of the IM4Q Statewide Steering Committee are appointed by the Deputy Secretary of ODP. Non-voting members, select their own representative, who is approved by the Deputy Secretary. For voting purposes, a majority of voting members must be present. Voting members elect a committee chair and co-chair. In the absence of the chair, the co-chair conducts the meeting. The committee operates using Robert's Rules of Order. The Committee meets three times a year with additional meetings called as necessary. The chair determines when it is necessary to form subcommittees and workgroups. Notes on the meetings are taken and shared with the IM4Q community through IM4Q Announcements.

Each year, the chairperson(s) asks the Committee members if they wish to serve on the committee again. The chairperson(s) decides if a Committee member is to be considered for reappointment based upon attendance at meetings and level of meaningful involvement. The chairperson(s), with input from the Committee members, proposes a slate of Committee members. The slate is voted upon by the voting members of the Committee at the last Committee meeting of the calendar year and is presented to ODP for final approval. Recommendations for filling vacancies on the Committee are made by the vote of the remaining voting members and submitted to the Deputy Secretary of ODP for approval.

The Statewide Steering Committee's roles and responsibilities are to:

- Provide approval or disapproval of all Local Programs selected by the AEs to ODP;
- Participate in the development and revision, as necessary, of survey tools;
- Issue recommendations to ODP from analysis of the statewide reports;
- Resolve conflict of interest questions for Local Programs;
- Develop a plan for external evaluation of the statewide IM4Q program, as well as review the Technical Advisor's external evaluation summary report;
- Advise ODP on policies and procedures for independent monitoring for quality;
- Hold necessary meetings to conduct the business of the committee; and
- Participate in the Annual Statewide Training.

### **IM4Q Management Committee**

The Management Committee collaborates with ODP on how IM4Q is being implemented. The Committee members represent Local Programs, Administrative Entities, SCOs, Technical Advisors, Statewide Provider Associations, and ODP Central Office, Regional Office, and State

Center personnel. The committee meets three times per year. Notes of the meetings are taken and shared with the IM4Q community through IM4Q Announcements.

Membership is determined by recommendations of existing members and approval by the entire committee. There is an emphasis on having statewide representation by including members from each region. When a new member is chosen to replace an existing member, emphasis will be placed on selecting from the same region and with sufficient experience with IM4Q.

Key functions of the Management Committee are to:

- Report on IM4Q practices and program implementation;
- Advise ODP on issues and concerns;
- Review draft protocols and system changes;
- Recommend actions to promote quality improvement within the service system related to IM4Q findings and practices; and
- Review aggregate reports and summary report of external evaluations of Local Programs.

### **Providers of Service**

Providers of service participate in the IM4Q process in a number of ways. Direct support professionals and program supervisors in residential/habilitation programs provide assistance to the Local Program in scheduling team interview visits, understanding the individual's communication style and preferences, and answering certain survey questions on the survey instruments when the individual is unable to do so independently. Provider association representatives participate on the Statewide Steering Committee and the Management Committee and other related workgroups and subcommittees.

Key functions of providers of service are to:

- Assist in scheduling monitoring visits when needed;
- Explain IM4Q to individuals receiving services and their families;
- Support individuals during the interview process when needed;
- Utilize provider-level reports for quality improvement purposes, in accordance with quality management responsibilities established under contract or agreement with the Department of Human Services or ODP; and
- Address considerations that result from IM4Q interviews.

## **Section Three: IM4Q Operating Guidelines**

### **Introduction**

This section is designed to help each Local Program develop and operate its program. Many of these protocols have been utilized by Local Programs since the inception of the pilot projects in 1999. However, the guiding principle of a “spirit of continual learning” is still very much a part of IM4Q.

### **Local Program and AE-Specific Practices**

#### **Local Program Selection Criteria**

Local Programs are selected by the AE, recommended by ODP, and approved by the Statewide Steering Committee.

To be a Local Program, the selected non-profit agency must:

- Be independent of the ODP service system as defined in Section One: Program Summary, under Guiding Principles for IM4Q;
- Have no conflict of interest on the administrative or board level that would compromise its independence as a Local Program;
- Demonstrate the ability to consistently perform work functions prescribed by ODP;
- Ensure independent individual and family participation on its monitoring teams and governing board; and
- Comport with other requirements established in the standard Request for Proposal (RFP) to Participate in Pennsylvania’s Independent Monitoring for Quality Program (Appendix F).

#### **Program Independence and Conflicts of Interest**

All efforts must be made to ensure that the Local Program is without any conflicts of interest. The Merriam Webster’s Collegiate Dictionary defines conflict of interest as “a conflict between the private interests and the official responsibilities of a person in a position of trust”. Local Programs must make conscious efforts to minimize particular conflicts which could lead to inaccuracy or lack of objectivity in monitoring. Individuals’ potential conflicts and biases should be clearly defined and addressed.

Each Local Program, under the direction of their governing board or advisory committee, will identify potential conflicts of interest with provider agencies, as well as in the selection of team members, and in team member monitoring assignments. If conflicts exist, then the Local Program will determine how to address such conflict. The following guidelines are offered to the Local Program as a way to prevent or minimize potential conflicts of interest.

#### **Local IM4Q Program Conflict of Interest Guidelines**

To be selected and approved as a Local Program, the non-profit agency cannot provide a direct service for individuals with intellectual disabilities or an administrative support service for ODP, its agents, or providers of service without safeguards established under contract.

A direct service is defined as an intellectual disability service which is provided through ODP Waiver funding.

After July 1, 2015, a non-profit agency which is not already providing IM4Q services will be ineligible to be a Local Program if the agency is certified by the Department of Human Services to provide Waiver or ICF/ID services anywhere in the state. A Local Program established prior to July 1, 2015 can continue to provide a direct service that it was authorized to provide prior to July 1, 2015 on the condition that the non-profit agency providing IM4Q services agrees under contract not to provide the direct service in the county or counties where the agency's local program operates. Any Local Program can provide base-funded services as defined in the ODP Service Definitions Bulletin, or any Department-approved revisions, but only in a county or counties where the Local Program does not operate.

The following provisions, effective July 1, 2015 and thereafter, must be included in the contract between the AE and the agency providing IM4Q services:

- Any new agency providing IM4Q services agrees that it will not provide any Waiver or ICF/ID services in the county or counties where the Local Program operates for the duration of the contract to provide IM4Q services;
- Any agency providing IM4Q services that began prior to July 1, 2015 who provides waiver or /ID services, must develop written safeguards against conflict between the Local IM4Q Program and the direct services.
- The agency providing IM4Q services understands that providing direct services that do not comport with ODP requirements constitutes a violation of its independence that will lead to termination of the Local Program or termination of service delivery by ODP in consultation with the Local Program, the AE, and the Statewide Steering Committee;
- The agency providing IM4Q services agrees that it will report to the AE any direct service provided to an individual who is registered with the AE in which the Local Program operates or a change in its authorization to provide services in the county or counties where the IM4Q operates; and
- The agency providing IM4Q services agrees that it will obtain the services of another Local Program to conduct an interview for an individual who receives direct services, in any county or counties where the local program is authorized to provide direct services.

In addition, when administrative safeguards are stated explicitly in the IM4Q contract to preserve the Local Program's independence and prevent conflict of interest, the following services and forms of Local Program participation are allowable:

- Health Care Quality Unit (HCQU) services under contract with ODP;
- Incident management reporting, investigation, and review services operated under ODP regulations and policy;
- Administrative oversight services to an AE, such as contract monitoring and independent program/fiscal audit services;
- Representative payee services;
- Early Intervention services for infants and toddlers, birth through age 3, and pre-school services not funded through ODP (waiver or base funding);
- Social and recreational services;
- Training and technical assistance services funded under contract with ODP or an AE;
- Post-secondary university, college or trade school programs that enroll individuals with intellectual disability, except when tuition or other university costs are funded through an ODP HCBS Waiver or ICF/ID;
- Independent or other monitoring services provided by a Local Program or sponsoring agency that are authorized by ODP, AE, AE MH/ID Advisory Board or agency outside of the

ODP service system, such as Consumer Satisfaction Teams (CST), other monitoring not funded by ODP;

- Participation of IM4Q staff and monitors on quality workgroups and committees, including committees formed by an AE or provider consortium, as long as the participation is not paid through a salary or honorarium;
- Participation of Local Program monitors as student interns with a provider of direct service as long as the student is not assigned to an interview with an individual receiving services from the same agency;
- Advocacy services provided by a chapter of The Arc, self-advocacy association, UCP, CIL, mental health association, or similar organization;
- All services provided for individuals with funds authorized by the ODP Bureau of Autism Services (BAS), including services authorized under a BAS HCBS Waiver;
- All services provided by other program offices within the Department of Human Services other than ODP; and
- Services provided with non-public funds such as private donations and grants.

If a conflict of interest is identified, the matter must be reviewed expeditiously between the Local Program board and the AE, with notification to ODP and the Technical Advisors. If the conflict cannot be resolved in a manner that comports with the IM4Q Manual, the AE and Local Program are responsible to bring the issue to the attention of the ODP Regional Coordinator and the Technical Advisors. Once ODP or the Technical Advisors, the AE, and ODP Regional Coordinator are advised of the conflict of interest, they will review the circumstances and issue a recommendation for preserving program independence. The ODP Regional Coordinator will convene a meeting to discuss the situation and provide guidance if needed. To ensure statewide consistency in its assessment of Local Program independence, all requests to ODP for a conflict of interest/program independence determination by a Local Program or AE will be reviewed by ODP Central Office in consultation with the Local Program, the AE, ODP regional personnel, the Technical Advisors and the Statewide Steering Committee. The notice of the determination will be made to the Local Program and the AE by the ODP Regional Program Manager (RPM) or designee.

Any Local Program that is considering an administrative or program change that might affect the agency's IM4Q independence must advise the AE, the ODP Regional Coordinator, and the Technical Advisors before the administrative change occurs or is finalized under an agreement or contract. Effective July 1, 2015, the following program changes must be reported to the ODP Regional Coordinator, AE, and Technical Advisors:

- Merging of a Local Program with an agency that provides direct services funded by an ODP HCBS Waiver;
- Enrollment by the Local Program as a provider of waiver or ICF/ID services into an agreement to conduct administrative support services for an AE, ICF/ID, or provides ODP-funded services where the Local Program operates; and
- Changes in work responsibility of the Local Program Coordinator or IM4Q board that would require the Local Program Coordinator or board to assume responsibility for services authorized under an ODP HCBS waiver.

Beginning July 1, 2015, any agency that provides IM4Q and other administrative or direct services that are used by individuals with intellectual disability must list these other services in a work statement in its annual contract with the AE, together with administrative safeguards that the program will have in place to preserve the independence of the Local Program in light of these additional services. The agency is responsible to ensure that all administrative and direct

services used by individuals receiving ODP-funded services are listed, even when these services are approved by ODP or the AE. Safeguards must include written policy and practices that are required by ODP or the AE to ensure that information from other agency programs are not passed on to the Local Program and team members. A standard form for providing this information will be available through the ODP Regional Coordinator upon request.

The Local Program Coordinator is responsible to ensure that each monitoring team member has no conflict of interest that would jeopardize the team member's ability to make independent judgments during the IM4Q interview and reporting process. If a conflict of interest exists, appropriate safeguards are developed and included in the contract.

The Local Program Coordinator is also responsible to consider team member conflict of interest situations on an individual basis. There is an increased possibility of issues when human service professionals become team members. If considering a human service professional to become a team member, be aware of such conflicts, as well as the issue of confidentiality. The following points must be considered to determine if any conflict of interest exists:

- Past or present involvement with a provider agency that is responsible for services to the individual, e.g. ODP program monitor, supports coordinator, or certified investigator, or that is responsible for services to an individual being interviewed;
- Past or present involvement in representing an individual being interviewed in an advocacy, paid support, or legal capacity;
- Anyone having a reason that may make it difficult to make critical judgments of a service provider; and
- Bias of a monitoring team member about a certain provider, individual being interviewed, or administrative organization that would affect critical and independent judgment.

### **Recruitment and Selection of Monitoring Team Members**

To recruit team members the following activities may be helpful:

- Advertise in local newspapers, bulletins, electronic bulletin boards, social networking websites, and similar publications reaching diverse communities and groups;
- Conduct planned outreach to advocacy groups and diverse community groups;
- Solicit and use interested individuals and contacts, including individuals and family members who are interviewed; and
- Advertise and reach out to high schools, colleges, clubs, civic organizations, and places of worship.

Each monitoring team must include at least one person with a disability or a family member of an individual who has a disability, with a preference for a family member of an individual with an intellectual disability. Family members can be parents, brothers/sisters, grandparents, aunts/uncles, or other relatives of a person with an intellectual disability. Family members do not have to live in the county in which they are a team member. For parents of children not in the residential system, being on a team is a great learning opportunity.

Persons who do not currently work in human services are preferred candidates for monitoring teams. Homemakers, high school students (18 years and older), college students, retired persons, and other members of the community, either living in the county or neighboring counties, should be considered. Community and business leaders are also welcome to participate.

All monitoring team members must be assigned by the Local Program Coordinator or designee using a process that ensures each team member is:

- Clear of any conflict of interest with the individual or agency being visited;
- Able to carry out responsibilities in a confidential manner in accordance with HIPAA and other confidentiality requirements;
- Instructed in the use of the survey tools and interview protocols they are expected to follow, including protocols for reporting major concerns with suspected health and safety issues;
- Instructed in the principles and practices of the ODP service system, including the role of IM4Q in the ODP Quality Improvement System;
- Cleared to conduct an IM4Q interview in accordance with the Local Program board and/or committee. This includes completion of criminal background clearance requirements, including child abuse clearances, if applicable;
- Issued identification to document him or herself as a monitoring team member at the interview site; and
- Matched to the individual being interviewed and the interview situation, taking into account the pre-survey information provided by SCs, the provider of service, family members, and AE personnel.

Each team member is responsible to present himself/herself in an appropriate manner and to conduct the IM4Q functions assigned to them. Each member is expected to be:

- Courteous and respectful of others involved in the interview;
- Dressed appropriately;
- On time for interviews, with materials needed and credentials attesting to his/her being a monitoring team member;
- A careful listener to the individual being interviewed and others regarding the individual's life;
- Respectful of personal private spaces such as an individual's bedroom, dresser or closet, refrigerator, or other closed space that the individual does not invite the monitor to open or view;
- Focused on their monitoring role and not to enter into side conversations, judgments, giving of advice, unsolicited personal stories or criticism; and
- Mindful of the confidential nature of the information they receive, as well as their opinions regarding the interview experience.

Team members are expected to report breaches of expected protocol to the Local Program Coordinator or designee, including any occurrence where an interview participant expresses dissatisfaction with the demeanor, attitude or conduct of a team member.

### **Compensation of Local Program Staff/Team Members**

The Local Program Coordinator, other IM4Q management personnel, and data entry personnel are expected to hold paid positions with salary and benefits determined in cooperation with the agency executive personnel and the Local Program board. Monitoring team members are expected to be compensated for their work. Payment of all employees and contractors must be in accordance with applicable state and federal laws. Monitoring team members may be compensated or reimbursed for expenses at the discretion of the Local Program.

## **Contracts with AEs**

Each Local Program has a contract with the AE that comports with the requirements of the Fiscal Manual for the County MH/ID Program, 55 PA Code Chapter 4300 and/or existing waiver fiscal regulations (Chapter 51 or 6100). Contracts are for a period of one fiscal year and are extended based on the IM4Q Program's fulfillment of its required functions and responsibilities.

Once the contract is established, the roles, responsibilities, payment rates, and procedures should be explicitly stated.

Any conflicts of interest should be disclosed and safeguards clearly explained.

A Local Program which elects to not renew its contract with the AE is expected to provide the AE and ODP with a minimum of 90-day notice before the end of the fiscal year (March 31st). The Local Program is expected to complete its contractual obligations for the fiscal year, unless otherwise directed by ODP.

If, during the program year, the Local Program finds that it is unable to fulfill its contractual obligations, it must notify the AE, ODP, and Technical Advisors. The Local Program is expected to consult with ODP and the Technical Advisors to determine whether other actions short of termination can be instituted to resolve the situation.

An AE can terminate its contract with a Local Program or begin the search for another Local Program. After consultation with ODP and the Technical Advisors, the AE is authorized to terminate its contract with a Local Program based on the following:

- Loss of the Local Program's status as an independent program, including failure to comply with corrective actions to address a conflict of interest or program independence situation;
- Failure of the Local Program to fulfill its responsibilities as indicated in this Manual;
- Failure of the Local Program to meet contractual obligations; or
- Failure of the Local Program to comply with other local, state and federal requirements.

If a contract is terminated, the AE is responsible to ensure that a new Local Program is selected as soon as possible. The AE is expected to issue a Request for Proposal to Provide IM4Q Services (Appendix F) to identify qualified candidates for the program. The Statewide Steering Committee is required to approve the selection of the new Local Program.

The AE will include a process in the contract in which a Local Program can pursue any grievance pertaining to its contract concerns.

## **Annual IM4Q Survey Cycle**

IM4Q follows an annual survey cycle that corresponds to the state fiscal year, July 1 to June 30. Specific dates for opening and closing the annual cycle in HCSIS and ODESA are subject to change based on ODP requirements, resources, and other conditions.

The following table summarizes the major activities that are generally completed in the course of each fiscal year survey cycle:

IM4Q FY Cycle Year (July 1 through June 30) Activity

Tentative Date	IM4Q Activity
July	<ul style="list-style-type: none"> <li>• IM4Q Annual Statewide Training, where IM4Q stakeholders receive information, technical assistance, and training, is held.</li> <li>• Joint Statewide Steering and Management Committee meeting occurs prior to the Annual Statewide Training.</li> <li>• ODP issues HCSIS-drawn sample of individuals who can be considered for interviews by sample subsets for the fiscal year to each AE/County Program.</li> <li>• ODP issues HCSIS-drawn State Center samples to State Center coordinators to review and share with local Programs.</li> <li>• Technical Advisors prepare survey instruments for release to the field.</li> <li>• ODP issues Proposed Annual IM4Q Sample Allocation List for the current fiscal year to AEs and Local Programs. The list contains the number of individuals, by sample subset that ODP expects to have funded for the IM4Q cycle. Subsets are generally established for Independent Monitoring, the Person/Family Directed Supports (P/FDS) Waiver, any current pilot surveys, and the National Core Indicators (NCI) Adult Consumer Survey. These numbers are contingent upon a final budget enacted by the General Assembly and a revised final sample allocation list may need to be issued at a later date.</li> </ul>
August	<ul style="list-style-type: none"> <li>• ODP issues current survey tools and other relevant materials.</li> <li>• ODP and Technical Advisors provide training on survey tool changes and new protocols.</li> <li>• Local Program Coordinators schedule and conduct monitor training.</li> </ul>
September	<ul style="list-style-type: none"> <li>• Survey data in HCSIS and ODESA are released to Technical Advisors for preparation of IM4Q Summary Reports.</li> <li>• AEs provide Local Programs with the list of individuals to be contacted for IM4Q survey visits.</li> <li>• IM4Q teams schedule and begin survey interviews.</li> <li>• State Center IM4Q visits begin.</li> </ul>
October	<ul style="list-style-type: none"> <li>• ODESA data entry opens for current year.</li> <li>• Data entry cycle opens in HCSIS for pre-surveys and considerations.</li> <li>• 1<sup>st</sup> round of Regional, Statewide Steering Committee, and Management Committee meetings occur.</li> </ul>
December	<ul style="list-style-type: none"> <li>• Technical Advisors submit IM4Q Summary Report for prior fiscal year to ODP for review and approval.</li> <li>• HSRI releases the NCI Report to ODP for the prior year.</li> </ul>
January	<ul style="list-style-type: none"> <li>• State Summary Report and NCI Reports are released to the AE/County Programs, local programs and the public.</li> <li>• 2<sup>nd</sup> round of IM4Q Regional Statewide Steering Committee, and Management meetings occur.</li> </ul>

	<ul style="list-style-type: none"> <li>Statewide Steering Committee submits recommendations based on Annual Summary to ODP.</li> </ul>
February	<ul style="list-style-type: none"> <li>State Center IM4Q State Summary Report is issued.</li> </ul>
April	<ul style="list-style-type: none"> <li>AE IM4Q Summary Reports for the prior fiscal year cycle are issued.</li> <li>3<sup>rd</sup> round of IM4Q Regional, Statewide Steering Committee, and Management Committee meetings occur.</li> </ul>
June	<ul style="list-style-type: none"> <li>All survey visits and data entry are completed and finalized in HCSIS and ODESA by June 30.</li> </ul>
July	<ul style="list-style-type: none"> <li>Begin new cycle.</li> </ul>

### **Annual HCSIS Sample Selection and Survey Activity**

The number of individuals in the annual IM4Q sample is determined by ODP in consultation with the Technical Advisors. ODP is responsible to:

- Determine the sample size, composition, and criteria for each sample subset;
- Issue Proposed Annual IM4Q Sample Allocation to each AE and Local Program;
- Ensure that samples are organized and shared in a secure and appropriate fashion;
- Issue annual statewide sample instructions;
- Ensure that AE and Local Programs have appropriate user rights to access demographic information for IM4Q purposes;
- Provide technical assistance to AE and Local Programs in managing IM4Q sample functions; and
- Provide AE and state center sample lists to HSRI for loading into ODESA, ensuring that no identifying information is included.

The AE is responsible to:

- Review and screen HCSIS-drawn samples to ensure individuals listed on the sample list meet ODP sampling eligibility criteria;
- Maintain accurate demographic records in HCSIS for use in the IM4Q sampling process and report inconsistencies with sample instructions and problems with the sample lists to the ODP Regional Coordinator;
- Provide the Local Program with timely consumer pre-survey information needed to schedule survey visits in a timely manner;
- Correct HCSIS errors that become evident when reviewing sample information; and
- Request redrawn samples and technical assistance from ODP.

**Neither the AE nor the Local Program is authorized to modify the sample in any way that affects the sampling criteria.**

The IM4Q Program is responsible to:

- Review the sample for duplication and other inaccuracies;
- Advise the AE and ODP Regional Coordinator of problems or issues with the sample using a Sample Discrepancy Form available by contacting the ODP Regional Coordinator;
- Conduct interviews with individuals on the sample list in accordance with ODP instructions;
- Advise the AE, in accordance with ODP instructions, when an individual on the sample list cannot be visited due to reasons such as the individual's health, decision not to participate, or other reason; and

- Complete the IM4Q Monthly Reporting Form and submit copies to the ODP Regional Coordinator and AE IM4Q Coordinator.

ODP periodically authorizes pilot surveys and special studies to obtain information on satisfaction and other outcomes for individuals in the ODP service system. Local Programs can also contract or arrange to participate in other independent survey activities outside of the ODP system (e.g., Consumer Satisfaction Teams; Money Follows the Person project). The AE can also arrange for the Local Program to include additional questions during their survey visits with prior approval of the Local Program's governing board, AE, IM4Q Technical Advisors, and the ODP Regional Coordinator.

### **Communication with IM4Q Programs**

Given the independent nature of the Local Program, direct written and verbal communications between ODP and Local Programs is a necessary practice. The ODP Regional Coordinator has the authority to address the AE's performance of its IM4Q duties. ODP will ensure that the AE is provided with immediate notification and the opportunity to modify any factual inaccuracies or provide additional information to clarify the performance issues. Typically, the Technical Advisors and ODP Central Office Coordinators are included in such communications.

Local Program and AE IM4Q Coordinators communicate on an ongoing basis. Local Program Coordinators may also communicate directly with providers of service, including supports coordinators of individuals receiving services, in accordance with the protocols established and approved by the AE. These communications are limited to information related to IM4Q pre-surveys and considerations.

Local Program Coordinators may also communicate directly with individuals receiving services and their families to determine whether IM4Q considerations are being addressed in a timely manner and to the satisfaction of the individual and his/her family. The Local Program is responsible to advise the AE regarding these contacts and to ensure that its communications with individuals receiving services and their families aligns with protocols established with the AE for this purpose.

Communication also occurs through the issuance of IM4Q Announcements, quarterly regional meetings that involve Local Program and AE Coordinators, ODP Regional Coordinators, and Technical Advisors. Local Programs are responsible to ensure that IM4Q Announcements are reviewed, shared, and followed. At least one representative from each Local Program is expected to attend all quarterly regional meetings and the Annual Statewide Training. AEs are expected to ensure that their IM4Q Coordinators attend the quarterly regional meetings and Annual Statewide Training, and that IM4Q Announcements related to AE responsibilities are followed.

ODP, in coordination with the Technical Advisors, ensures that Local Program and AE IM4Q Coordinators have information concerning IM4Q updates and changes in a timely fashion. This information is communicated via IM4Q Announcements, regional meetings, training and technical assistance opportunities, and the Annual Statewide Training.

### **Training and Technical Assistance**

There are various forms of training and technical assistance provided by different stakeholders.

A comprehensive compilation of varied training materials relevant to IM4Q, titled *The ODP IM4Q Training Resource Guide*, can be obtained from the Technical Advisors or ODP Regional Coordinators.

The Local Program is responsible to ensure that all monitoring team members have adequate training and technical assistance to carry out their responsibilities. The Local Program ensures that each team member receives an orientation that includes the following information before the team member is assigned to conduct an IM4Q interview:

- The principles of the ODP service system and how it functions;
- The role of the Local Program within the community service system;
- How the Local Program links to the ODP and AE Quality Frameworks;
- How to appropriately record interview responses, observations and considerations for data entry;
- Communicating with individuals who do not use traditional communication;
- Developing and writing considerations;
- Ongoing training as needed;
- Changes to survey instruments and protocols;
- Changes to survey process;
- Provide access to ongoing online training opportunities as needed; and
- Training to supports coordinators and providers.

The Local Program is responsible to ensure that each monitoring team member receives training on changes to survey instruments and protocols before conducting IM4Q interviews in a new fiscal year. The Local Program is also responsible to ensure that training materials and methods are accommodated to each team member's needs, abilities, and individual circumstances. The College of Direct Support (CDS) is available at no cost to the Local Programs (<http://www.collegeofdirectsupport.com/pa/>). Contact the Technical Advisors for information on registering for CDS.

The Local Program is authorized to arrange for ongoing training to enhance team member understanding of promising practices, quality initiatives, and service trends within the service system. This includes training and technical assistance provided by the AE, Technical Advisors, provider agencies, and ODP.

### **Administrative Entities (AEs):**

The AE is a resource for information for individuals, families, supports coordinators, providers and trainings upon request. The AEs, in collaboration with the Local Programs, are responsible for the training of SCs and providers.

### **ODP and Central Office Regional Coordinators:**

ODP Central Office and Regional Coordinators provide training and technical assistance to Local Programs and AEs regarding IM4Q practices and protocols, including the application of quality management principles and practices, to Local Program operations.

### **Supports Coordination Organizations (SCOs):**

Supports Coordination Organizations train all supports coordinators on the principles of IM4Q and provide technical assistance on responding to considerations in HCSIS.

## **Technical Advisors:**

Technical Advisors provide training and technical assistance for:

- Monitoring team members on the use of the survey instruments;
- Local Programs and AE on considerations in HCSIS;
- SCOs and providers;
- The use of IM4Q Summary Reports and Consideration Reports in provider, AE, and State Quality Frameworks; and
- The use and interpretation of IM4Q Summary Reports and data in ODESA.

## **Research Standards and Data Security**

IM4Q adheres to ethical research standards, including standards related to the confidentiality of records, interviewing, reporting and other aspects of its operations. Survey instruments and processes are approved by an Institutional Review Board (IRB) or a similar panel to ensure the protection of human subjects.

IM4Q data integrity is ensured through secure web-based data entry and reporting systems in HCSIS and ODESA, training and technical assistance provided to data entry personnel, user rights security, secure email requirements, protocols for requests for research data and other administrative safeguards. Local Program, AE, and ODP staff assigned to IM4Q is expected to follow established protocols to maintain data and information security consistent with ODP policy.

Local Programs must store confidential IM4Q information (e.g., sample lists, completed pre-surveys, surveys, and other written notes) in a secure location for five years. To effectively manage record storage, Local Programs may create PDFs from hard copies and store them in a secure electronic environment. ODP does not recommend the use of flash-drives for storage, as there is potential risk for loss and misuse of individuals' confidential information. Local Programs should also check their internal security protocols for secure storage of information.

Anyone requesting IM4Q data are advised to contact ODP Central Office or the contracted entity. The request must be made in writing. Please refer to Appendix E: Requesting IM4Q Data, Analysis, and Reports.

## **Local Program Evaluation**

Each Local Program participates in an external evaluation of its program on a regular basis in accordance with instructions provided by ODP, in consultation with the Technical Advisors. Annual external evaluations lead to action plans that are reviewed with the Technical Advisors. External evaluations have included peer reviews and assessments by outside experts.

Each Local Program also:

- Obtains evaluations from interview respondents through a postcard evaluation process; postcards may be obtained by contacting one of the technical advisors (see Appendix H – Independent Monitoring Survey – Evaluation Card).
- Completes an ODP Annual Statistical Report template which contains information on the composition of the IM4Q team and board membership, training, payment structures, and quality improvement actions. The template is issued each year by ODP Central Office.

- Completes an IM4Q Monthly Reporting Form on the number of finalized surveys, individuals who refused visits, and other pertinent information. This form is used by the ODP Regional Coordinator to track survey finalization status, trends and issues, as well as by the Technical Advisors to review any comments regarding the survey instruments. This report is electronically forwarded to the ODP Regional Coordinator by the end of the first week following the reporting month. Even if no activity has occurred in that reporting month, the Local Program should submit a report indicating this information. A copy of the form is made available at the beginning of each survey cycle.
- Receives an in-person program review from the Technical Advisors and their ODP Regional Coordinator every two to three years, which includes a review process utilizing an agenda of questions and review of relevant documents. The review includes relevant Local Program staff, AEs, and ODP Regional Coordinators. Reports are generated requesting a corrective action plan from the Local Program in response, which is then reviewed and approved by the Technical Advisors. Program reviews may occur more frequently as needed or requested.

## **Survey Instruments and Interview Practices**

### **Survey Instruments Used by IM4Q**

IM4Q uses the Essential Data Elements (EDE) as the main survey instrument for assessing satisfaction and outcomes for individuals receiving services and their families, friends and guardians. Developed by the Institute on Disabilities and ODP in 1999, and based on the National Core Indicators Adult Consumer Survey, the EDE is used with individuals age 3 and above, regardless of their living arrangement or services they receive.

Sections 1 and 2 of the EDE asks questions related to personal satisfaction, dignity, respect and rights and can only be answered by the individual receiving services. EDE questions in section 3 asks questions related to choice and control, section 4 about relationships, and section 5 about inclusion and are answered by the individual receiving services unless he/she is unable or unwilling to respond, and then a family/friend/advocate/staff member who knows the individual well can answer on the individual's behalf. Individuals with communication challenges are supported to provide their own responses to the greatest extent possible. Section 6 of the EDE consists of IM4Q team observations. The final EDE section is the Family/Friend/Guardian (F/F/G) Survey, which is typically a telephone survey conducted after the survey visit with permission of the individual receiving services, or it may be completed while on site and if necessary mailed out. A Spanish version of the EDE is available upon request.

The EDE is revised periodically by the Technical Advisors based on recommendations and feedback from Local Programs, AEs, ODP, and Statewide committees.

In addition to the EDE, IM4Q Programs also administer the NCI Adult Consumer Survey, the State Center Supplement, and pilot surveys as warranted.

### **Consent of Individuals Being Interviewed**

An individual receiving services can refuse to participate in an IM4Q interview at any time prior to the interview (when initially contacted or when asked on site by the team) or at any time during the interview. Consent to participate is indicated only verbally or through other alternative communication of the individual. For individuals unable to effectively communicate, consent is assumed and the team should proceed with the interview.

The Local Program offers the individual the choice to participate in an interview and should not accept a consent or refusal to participate from another entity on the individual's behalf. Guardian consent is not required; however, the guardian is kept informed of the process (see Appendix G for Letter to Legal Guardians). If a refusal occurs, the Local Program should attempt to explain the benefits of IM4Q to encourage consent. However, if the objection persists, Local Programs are advised to proceed to the next name on the sample list. Individuals who decide not to participate in an IM4Q interview remain on future sample lists in the event the individual should change his/her decision.

Individuals should be interviewed in their homes unless they or their families prefer that the interview takes place elsewhere. No provider agency, its staff, or any person who receives funding to support the individual has the authority to determine the location of the interview or to deny access to the individual. The AE is responsible to ensure that all providers of service are aware of their responsibility to ensure access to monitoring teams in accordance with the choice of the individual receiving services.

The Family/Friend/Guardian (FFG) Survey section of the EDE is completed for each individual unless he/she objects to having their family member, friend, or guardian interviewed. If the individual interviewed is unable to communicate an objection then it is assumed that the survey can be conducted. During the interview, a member of the monitoring team can complete Sections 1 and 2 with the individual while the other team member takes the family member, friend, or guardian to another area to complete the FFG survey. Otherwise, the FFG survey can be done at the end of the interview, or over the phone. A last resort, the survey can be mailed to the family, friend or guardian for completion. Only one FFG Survey can be completed per individual per survey cycle.

### **Confidentiality**

IM4Q ensures confidentiality of the information gathered through the survey process, including the individual being surveyed, his/her families, personnel providing services, and agency names and program locations. Confidentiality is adhered to by all IM4Q participants including monitoring team members, Local Program personnel, board members, Technical Advisors and ODP personnel. Statewide committee members are also bound by requirements of confidentiality.

All monitoring team members sign a confidentiality oath prior to conducting a team interview and inform the individual/family that the results of the interview are confidential. A copy of the standard confidentiality statement signed by monitoring team members is available on request from ODP. See Appendix I – Confidentiality Statement.

Confidentiality extends to the identity of the individual and family being surveyed except when there is a clear and present threat to health and welfare witnessed by the monitoring team. In these instances, the Local Program does provide the name of the individual when reporting the major concern to the AE.

Completed EDE and NCI surveys, notes and work papers used by monitoring teams are only subject to review by interview participants, legal guardians, Local Programs, Technical Advisors, or ODP staff. Considerations from the surveys are shared with the AE only when the individual being interviewed does not object to having this information shared. The individual or family member being interviewed can also indicate that only certain individuals or agencies are able to

see IM4Q Considerations with respect to the information they have shared with the team, as long as there are no health or safety concerns.

### **Family/Friend/Guardian Participation**

Family, friends, and guardians of the individual being surveyed are encouraged to participate in the IM4Q process. All survey participation is completely voluntary and confidential. The following are examples of how families, friends and guardians can participate in the IM4Q process:

- Attend the interview with the individual's permission;
- Complete a Family/Friend/Guardian Survey;
- Complete a National Core Indicators Family Survey (Family/Guardian Survey or Adult Family Survey), if individual is randomly selected;
- Participate as members of the Individual Support Plan (ISP) Team that reviews considerations for follow-up action; and
- Participate on IM4Q-related teams, boards and committees.

The Department of Human Services Office of General Counsel has concluded that no surrogate consent (including that of guardians) is needed in any circumstances for an IM4Q survey to be conducted with a willing participant. IM4Q participation is completely voluntary for the individual receiving services.

### **Interview Practices**

Interviews should be scheduled directly with the individual whenever possible and in the residential setting where they live. When this is not possible, then:

- If the person lives in a community home, the Local Program should contact the house supervisor to coordinate the arrangements;
- If the person lives in a private ICF/ID, the agency director is to be contacted to coordinate the arrangements;
- If the person participates in Lifesharing, the Lifesharing Specialist at the provider agency is to be contacted to coordinate the arrangements; or
- If the individual wishes to have the interview at his or her day program, the Local Program should contact the day program supervisor.

The Local Program is responsible to schedule an interview visit with the individual receiving services. Information to schedule the visit is provided by the AE or a supports coordinator through a written consumer pre-survey that consists of HCSIS-generated demographic information and additional information provided by the AE.

Monitoring team members should review the pre-survey for critical information that may have an impact on the interview (e.g. behaviors, communication, pets, interviewer preferences, etc.). The Local Program makes a phone call or personal contact to schedule the interview visit and explain the IM4Q process. Communication should be documented through telephone and correspondence logs to family members, guardians, provider agencies and/or the AEs/SCOs. Local Programs do not need permission of legal guardians to schedule or conduct an interview. However, programs must notify legal guardians of the scheduling an interview. (See Appendix G: Letter to Legal Guardians)

All interviews are conducted in settings and at times selected by the individual. The interview should also be convenient for family members or contact persons who will be accompanying the individual at the interview. Interviews should be scheduled directly with the individual whenever possible. Interviews with individuals who do not communicate in traditional ways should be scheduled with the agency where the individual lives or with their family member if they live at home. Interviews of adults are conducted in private, unless the individual being interviewed wants to be accompanied by an advocate, staff, family member, guardian or other person of their choice or if there are other reasons why an interview should not be conducted in private based on pre-survey information. Children must be interviewed in the presence of another adult. Ideally, interviews are best conducted in the individual's residence as a number of interview questions are associated with the home setting. For interviews that cannot occur in the individual's residence, the team should ask the individual or contact person for an alternate location, such as a coffee shop or a community program that the individual attends that affords privacy.

The Local Program can suggest an interview outside of the individual's home if conditions in the home are expected to be unsanitary, unsafe, or otherwise unworkable due to household work schedules, health conditions of household members, allergic conditions in the home, temporary construction, etc.

Before the survey visit begins, the monitoring team is responsible to determine the role of each member, whether it is to ask survey questions, to record individual responses, and/ or make observations.

### **Monitoring Team Visit Practices**

The monitoring team, before or after the interview, should drive around (even walk) the neighborhood and community in which the person lives as some questions on the EDE require such knowledge of the person's surroundings.

The monitoring team begins the interview visit with introductions and by explaining the purpose of their visit. They should also share a letter of introduction or other credentialing information attesting to their assignment as an IM4Q monitoring team member.

A team member explains how the survey visit will normally proceed, beginning with questions from the standardized survey, and a tour of the home (inside and out) and other personal areas, including the bedroom, if agreed to by the individual. The monitoring team should note that they may ask additional questions to those included in the EDE. Each interview visit takes approximately 1-2 hours, although longer visits may occur to ensure the participation of individuals with different communication styles and challenges.

The monitoring team ensures that the individual and others in attendance know that they can ask questions about the meaning of an EDE question or ask the question to be asked in another way if they don't understand it. Under no circumstances should a monitoring team interview more than one individual at a time.

If the monitoring team needs to use a recording device as an accommodation to verify answers, the team must ask permission to record the interview and be prepared to conduct the interview without a recording device if permission is not granted. Tape-recorded interviews must be maintained by the team member and the Local Program, consistent with the law, in a safe and secure place to preserve confidentiality.

A monitoring team member reads or reviews statements that accompany the EDE survey tool related to confidentiality, the use of the IM4Q information, the process by which considerations are shared, and the individual's right to participate in answering any or all questions.

The monitoring team is responsible to accommodate to the communication style of the individual to the greatest extent possible in how questions are asked and answers are communicated. This information may be found on the pre-survey or when the interview is scheduled, if applicable. The team should use the appropriate method to assist the individual in communicating, and make maximum use of assistive technology that the individual may use to communicate. Additional time to communicate is to be provided as needed.

If an individual being interviewed or another person at the interview requests to see the survey that is being completed, the team is authorized to provide a copy of the EDE or other survey tool to the individual for the duration of the interview. The blank EDE should be collected by the team before they leave the interview site.

After the interview is completed, the team should leave information authorized by ODP for the Local Program, a stamped interview evaluation postcard that can be sent back to the Local Program for quality improvement purposes. To receive the postcards, contact the ODP Regional Coordinator or the technical advisors. See Appendix H- Post Card for Evaluation.

### **Post-Interview Visit Team Practices**

The monitoring team is expected to meet after the interview to complete all surveys, ensuring that team responses are accurately reflected and agreed upon and that considerations are developed. Follow-up calls can be made to the individual to clarify information. Considerations should be developed based on information from the individual, family and staff or team members.

Each team is expected to provide the Local Program Coordinator with completed survey forms. The team is responsible to ensure that the completed surveys are accurate, completed to the best of their ability, and legible for purposes of data entry. Team considerations should also be submitted to the Local Program Coordinator at this time. In addition, if the team records any Major Concerns they need to follow their local program's policy in addressing such concerns.

### **Data Entry**

The Local Program is responsible to ensure that the pre-surveys and considerations are data entered into HCSIS and the final results of the survey visit are data entered into ODESA. The Program Coordinator is responsible to ensure that the survey data is accurately entered in a timely fashion and that Local Program personnel have the appropriate user rights for data entry and review. All Local Program data entry staff is responsible to comply with confidentiality and other HCSIS user rights safeguards established by the Department of Human Services and ODESA safeguards established by the Human Services Research Institute.

The Program Coordinator is responsible to ensure that all phases of the data entry process are monitored for quality assurance purposes. Each IM4Q visit should result in the completion of the following:

- Finalized pre-survey
- EDE or NCI Adult Consumer Survey
- Family/Friend/Guardian Survey

- Subset pilot survey (if applicable)
- Considerations
- State Center Supplement (if applicable)

The AE is responsible to pay only for surveys and pre-surveys that are finalized in HCSIS and ODESA by the due date established by ODP. Both the AE and the Local Program are responsible to review survey status reports in HCSIS to confirm that pre-surveys have been finalized and to inform the ODP Regional Coordinator when there are inconsistencies or inaccuracies based on this review. The AE may request a report of completed surveys from the Local Program to review the status of EDE, NCI, and other surveys entered into ODESA. The Local Program will provide the report directly from ODESA or, if necessary, request the data from the ODP Central Office Coordinator.

The Local Program is responsible for un-finalizing any pre-survey(s) determined to be finalized either prematurely or with inaccurate information. The Local Program must contact the ODP Central Office Coordinator or the Technical Advisors with a request that a specific pre-survey be un-finalized.

Technical assistance in assuring accurate and timely data entry is available by contacting the ODP Regional Coordinator or Technical Advisors.

### **Considerations**

Considerations are requests or perceived requests for change or improvement indicated by an individual, family, staff, or monitor. They may result in service changes or provide an opportunity to improve the quality of life of the individual. Considerations are completed in HCSIS after a pre-survey for the fiscal year has been completed and finalized. Neither an EDE nor an NCI Adult Consumer Survey needs to be entered for a consideration to be completed.

Capturing the considerations in HCSIS allows one central point for Local Programs and AEs to share information and confirm the status of considerations as part of the “Closing the Loop” process. Various alerts are used to notify each role of appropriate steps of the process. Primary Themes and Secondary Themes are available as drop-down boxes for considerations and are required fields. The *IM4Q Considerations Module: HCSIS Training Manual* (May 2012) is available from the ODP Central Office and Regional Coordinators for extensive training in how to use HCSIS for IM4Q.

Per training on the Harry M. settlement, monitors have the responsibility to report any issues with communication needs, including communication needs that may create a dangerous situation for an individual. If during a monitoring visit a team member identifies a communication need, it should be addressed under the “Communication Needs/Devices/Services” consideration theme in HCSIS. If the communication need is a major concern that may put an individual at risk, monitoring teams should report it via the normal Major Concerns reporting process.

Once a consideration is completed, AEs and provider agencies are able to request and access reports of information gathered through the consideration process. Each HCSIS role is only able to access certain reports.

The considerations section in HCSIS is not to be thought of as the only platform for communications around considerations. If additional verbal and email communications are

required between Local Programs and AEs/SCOs for clarification purposes, then they should be held.

### **Considerations for State Center Residents**

Originally, Local Programs recorded considerations for state center residents and submitted them to the Technical Advisors for data entry into HCSIS. Once the considerations were entered, the AE of registration and the supports coordinator would receive an alert that this had occurred and would conduct the necessary follow-up with the residents and state center staff. The Local Programs also sent copies of the considerations to the appropriate State Center Coordinator so that the resident's team could begin to address them. Communication between Local Programs and State Center Coordinators as well as between the supports coordinators and the State Center Coordinators was crucial for the closing the loop process to occur.

In 2015-2016, the Local Programs conducting surveys at the state centers were granted access to enter considerations for the individuals in HCSIS. Communication outside of HCSIS between the Local Programs, SCs, and State Center Coordinators is still crucial, as the State Center Coordinators do not have access to considerations in HCSIS.

### **Major Concerns with Health and Safety**

In coordination with the AE, each Local Program will develop a policy to address any Major Concerns regarding the health or safety of the person being monitored. As indicated in the EDE, Major Concerns include:

- Physical dangers within a residential site/home or place of community activity (e.g. broken stairs, plaster falling from the ceiling);
- Significant sanitation problems (e.g. plumbing problem, filthy environment, visible bug problems, rodent infestation);
- Evidence of physical abuse or neglect (e.g., unexplained bruises, poor dental care, and noticeable changes in weight);
- Evidence of psychological abuse (e.g. staff yelling at an individual, insulting language, restrictions placed on social activities); and
- Evidence of human rights violation (e.g., stealing of individual's funds or property).

The policy will require that the monitoring team report any Major Concern immediately to the AE, and that the AE respond within 24 hours to the issue. The AE is responsible to advise the Local Program on actions taken to address reports of this nature. Major Concerns are also to be entered as considerations in HCSIS; there is a specific category under which they are to be entered.

Unless a person is a mandated reporter in a capacity other than as a monitor or Local Program staff, he/she is not required to report Major Concerns to Adult Protective Services (APS). Under the law, a mandatory reporter is "...organization or group of people that use public funds and is paid, in part, to provide care and support to adults..." However, it is recommended that a call be placed to the APS hotline (800-490-8505) to ensure that appropriate follow-up is completed.

Monitoring teams will not leave an interview if they perceive any imminent threat of danger to the individual or anyone in the setting until such time as the individual is in a safe environment.

They will immediately report the danger to the appropriate parties, according to policy established by the Local Program and AE.

If a monitoring team is concerned for its own safety and cannot stay with the individual until a safe situation exists, the team is authorized to immediately leave the premises and call 911 for immediate assistance.

Local Programs are responsible to ensure that monitoring teams are advised to prepare an “exit strategy” in the rare instance that a team member feels unable to complete the survey visit. This exit strategy, which can be anticipated by a statement, phrase or gesture, would alert all team members to leave the premises, and needs to be known by all team members. Situations that result in engaging a team exit should be reported to the Local Program Coordinator, and when appropriate, followed up with the AE.

### **Local Program 10% Follow-up of Considerations**

In the fiscal year following the data collection, the Local Program is required to follow up with at least a 10% sample of individuals and families being interviewed to ensure considerations are addressed in accordance with the Local Program- and AE-established timelines and to the satisfaction of the individual/family. The follow-up may be a phone contact, letter, or a visit as determined by the standard practices agreed to between the Local Program and the AE. When the individual and or family are satisfied, the loop is considered closed. A follow-up practice should be reflected in the written Closing of the Loop Policy between the AE and Local Program.

When considerations are not being addressed to the satisfaction of the individual/family or in a timely fashion pursuant to the protocol, the Local Program brings its concern to the AE. When the AE is not responsive to the Local Program’s follow-up concern, or if the Local Program determines that the response does not satisfactorily address the concern of the individual interviewed and/or his/her guardian/family, the Local Program is responsible to bring this matter to the attention of the ODP Regional Coordinator, who will work directly with the AE in addressing the Local Program’s concern. In some instances, the Local Program Coordinator will develop a new consideration based upon the consideration that was not viewed as closed (completed) by the person/family interviewed

### **State and AE Summary Reports**

The contracted entity, as independent ODP Technical Advisors, completes an annual Statewide Summary Report and individual AE Summary Reports containing aggregate findings. All reports are generated from ODESA extracts issued by HSRI to the contracted entity from data entered by the Local Programs. Statewide summaries will be posted to ODP-designated websites and public announcements issued at such times.

The IM4Q Summary Report is reviewed by the IM4Q Statewide Steering Committee, which provides recommendations to ODP for statewide action based on the Summary Report findings. The IM4Q Statewide Summary Report is issued by ODP to all AEs, Local IM4Q Programs, the IM4Q Statewide Steering Committee, the IM4Q Management Committee, and other stakeholders. IM4Q Summary Reports are scheduled to be released within 6 months after the end of the survey year.

AE IM4Q Summary Reports are issued by the contracted entity to each AE after the end of the survey year. The AE IM4Q Summary Report includes aggregate findings specific to satisfaction and outcomes of the individuals interviewed in the AE's jurisdiction. The AE is responsible to make the report available to its provider community, individuals receiving services and their families participating in the surveys, its MH/ID Advisory Board, and other interested citizens and organizations. The AE is responsible to use the data from the AE IM4Q Summary Report, together with other information, to improve services and supports within the constructs of the AEs Quality Framework.

The contracted entity also issues supplemental reports for sample subsets and pilots (i.e. P/FDS Waiver and State Center) which are shared with AEs, Local IM4Q Programs, the IM4Q Statewide Steering Committee, the IM4Q Management Committee, and other stakeholders.

User-friendly IM4Q Summary Reports for individuals receiving services and their families are issued annually. The report contains a two-sided page summary of aggregate AE results from the Statewide and AE IM4Q Summary Reports. IM4Q results are depicted in both graphic and iconic formats to facilitate individual and family understanding. User-friendly reports are given to individuals at the IM4Q interview and families/friends/guardians as part of survey mailings. The reports are also very useful summaries for AE MH/ID Advisory Boards, Quality Councils, and other interested parties, and should be distributed by the AEs and Local Programs. User-friendly AE Summary Reports for individuals with intellectual disabilities and their families are also available.

## **Section 4: Appendices**

Appendix A: Glossary of Frequently Used Terms

Appendix B: IM4Q Program Structure and Processes

Appendix C: IM4Q-ISP Connection Practices

Appendix D: State Center Closing the Loop Process

Appendix E: Requesting IM4Q Data, Analysis, and Reports

Appendix F: Request for Proposal (RFP) to Provide IM4Q Services

Appendix G: Guardian Letter

Appendix H: IM4Q Evaluation Card

Appendix I: Confidentiality Statement

## **Appendix A: Glossary of Frequently Used Terms**

**Administrative Entity (AE):** The Department of Human Services has established AEs, as designees of ODP, to authorize services funded through the Home and Community Based Services (HCBS) Waivers for individuals with intellectual disabilities across the Commonwealth.

**Adult Protective Services (APS):** Refers to the Act of 2010 (APS) (35 P.S. §§ 10210.101), which protects adults ages 18-59 from abuse, neglect, exploitation, and abandonment.

**Advisory Board/Committee:** Each Local Program will have a board or board appointed separate advisory board/committee, comprised primarily of individuals with disabilities and family members of individuals with disabilities, to provide guidance and recommendations as to the functions of the program.

**AE Operating Agreement:** An agreement with ODP which outlines and acknowledges the responsibilities that AEs are compelled to complete with regards to all waiver services and administrative functions such as IM4Q.

**AE IM4Q Coordinator:** The staff assigned to complete IM4Q functions for the administrative entity.

**Annual IM4Q Survey Cycle:** IM4Q follows an annual survey cycle that corresponds to the state fiscal year, July 1 to June 30.

**Annual Statewide Training (AST):** Held each year in Harrisburg, IM4Q stakeholders receive information, technical assistance, and training on a variety of topics related to IM4Q.

**Annual Statistical Report:** A report completed by the Local Program after the conclusion of the survey cycle. It utilizes a template provided by ODP and includes information on surveys, staff demographics, training, payment of monitors, and quality management activities.

**Child Protective Services (CPS):** Refers to 23 PA CS Chapter 63, laws which protect children younger than 18 from abuse, neglect, exploitation, and abandonment.

**Closing the Loop (CTL):** A standard written process for addressing Local Program considerations and ensuring that this process is followed by providers, Supports Coordination Organizations (SCOs) and other AE personnel. The loop is not considered closed until the individual or family believes that it has been closed.

**College of Direct Support (CDS):** Offers a nationwide, online, competency-based training curriculum to enhance the skills and knowledge of Direct Support Professionals (DSPs), frontline supervisors, and managers supporting individuals with disabilities in community settings, and is used by IM4Q monitors for free training on a variety of useful topics.

**Conflict of Interest:** "A conflict between the private interests and the official responsibilities of a person in a position of trust" (Merriam Webster). Local Programs must make conscious efforts to minimize particular conflicts, which could lead to inaccuracy or lack of objectivity in monitoring. Individuals' potential conflicts and biases should be clearly defined and addressed. An agency contracted to provide IM4Q services for an AE must not provide direct services to individuals receiving base or waiver funding for intellectual disability services. Safeguards must also be put into place to avoid perceptions of conflict.

**Conflict-Free:** Providing no service or having no bias that would affect the ability of an agency or individual to perform IM4Q activities in an objective manner.

**Consideration:** An indication that the participant would like to make a positive change in his/her life. Considerations may also come from family members, paid support staff, or from monitoring team observations. With the participant's agreement, the suggested change(s) will be forwarded to the AE and SC, and, in turn, to the individual's support team. Appropriate service providers and support team members will assist the individual to take the necessary steps to attain that outcome.

**Consolidated Waiver:** A federally-approved 1915(c) waiver program designed to help individuals with intellectual disabilities age 3 and older to live more independently in their homes and communities.

**Consumer Pre-Survey:** A document completed by an SC to provide beneficial information, including demographic information and critical information that may have an impact on the interview (e.g. behaviors, communication, pets, interviewer preferences, etc.), to the Local Program for scheduling an interview.

**Consumer Satisfaction Team (CST):** An independent monitoring system used for persons receiving mental health services. These teams may also provide IM4Q services.

**Contracted Entity:** An organization contracted by the ODP to provide technical assistance to AEs and Local Programs, as well as perform critical functions statewide, including data analysis, report generation and dissemination.

**Cost of Living Adjustments (COLAs):** Increase in the per survey cost to more adequately reflect the work required to complete the IM4Q survey process.

**County MH/ID Advisory Board:** The board works to develop continuing plans for the MH/ID program and to make recommendations to county commissioners regarding the program. It also reviews the performance of the MH/ID program and recommends a system of program evaluation.

**Data Collection:** The collection of independent monitoring information, from surveys and interviews, by the Local Program staff.

**Data Entry:** The process of inputting information gathered during data collection into the secure, web-based systems (HCSIS and ODESA) utilized by ODP for IM4Q purposes.

**Department of Human Services (DHS):** The state governmental department under which ODP is located.

**Disability Rights Network (DRN):** A federally funded agency created to provide protection and advocacy to people with disabilities to ensure their right to live in their communities with the services they need, to receive a full and inclusive education, to live free of discrimination, abuse and neglect, and to have control and self-determination over their services.

**Essential Data Elements (EDE):** The instrument used by the monitoring team to interview identified people in the AE sample. This instrument incorporates all National Core Indicator

questions, as well as questions specifically developed by the ODP contracted entity with input from ODP, AEs, and Local Programs.

**Everyday Lives:** The vision of ODP.

**External Evaluations:** Regular activities, designated by ODP and the Technical Advisors that Local Programs complete to determine any improvements which could be made to their internal processes. These could include face-to-face peer reviews or surveys to specific groups such as supports coordinators.

**Family/Friend/Guardian Survey (FFG):** A survey that, with the individual's permission, may be used to interview a family member, friend, or guardian. The survey may be completed either while interviewing the individual or during a subsequent phone interview.

**Federal Financial Participation (FFP):** A combination of federal and state funding for which supports coordination services are eligible through the Home and Community Based Services Waiver.

**Feedback Form:** A form included in the EDE which allows team members to provide feedback to the Local Program Coordinator about the monitoring process and the Essential Data Elements instrument.

**Health Care Quality Units (HCQUs):** Agencies that work to support and improve the health information and knowledge for the intellectual disability community service system.

**Health Insurance Privacy and Accountability Act (HIPAA):** A federal act that prevents confidential and identifying health information from being made public.

**Home and Community Services Information System (HCSIS):** The secure web-based data entry system used by ODP which contains information on PA residents receiving ID services. It is used to create samples for the IM4Q and NCI surveys, and Local Programs enter pre-survey information and considerations into it.

**Human Services Research Institute (HSRI):** The organization that develops and implements National Core Indicators, including issuance of the NCI surveys and operation of the ODESA data entry system.

**IM4Q Management Committee:** This committee meets to discuss the day-to-day operations of the IM4Q process. It is comprised of Local Program and AE representatives from each region, SCOs, provider agencies, Technical Advisors, and ODP IM4Q Coordinators.

**IM4Q Sample:** A randomly-drawn group of individuals in HCSIS and receiving services in an AE to participate in an IM4Q survey.

**IM4Q Sample Subset:** One of the separate lists included in a sample (e.g. State Center, P/FDS, NCI).

**IM4Q Training Resource Guide:** A compilation, created by the Technical Advisors, of training resources and best practices employed by Local Programs.

**Incident Management (IM):** The activities of an organization to identify, analyze, and correct hazards to prevent a future re-occurrence.

**Independent Monitoring:** The term used in the ODP Multi-Year Plan, Recommendation #7, meaning “a local monitoring team that is independent of the local service system and that is made up of a majority of individuals/family members. Outcomes for people and individual/family satisfaction should be the major focus of the assessments.”

**Independent Monitoring for Quality (IM4Q):** This statewide program is part of the Pennsylvania Intellectual Disability System Quality Framework. Independent agencies interview randomly-chosen individuals receiving services to obtain their thoughts on their quality of life and of the service system.

**Individual Support Plan (ISP):** An individual’s summary of their planned services (as well as preferences, outcomes, health, safety and medical information), identified as a result of review by the individual, family and plan team members.

**Institutional Review Board (IRB):** A committee that has been formally designated to approve, monitor, and review biomedical and behavioral research involving human subjects. It assures that appropriate steps are taken to protect the rights and welfare of humans participating as subjects in a research study. It promotes fully informed and voluntary participation by prospective subjects.

**Intermediate Care Facilities for the Intellectually Disabled (ICFs/ID):** State-operated or non-state operated facilities, licensed by the Department of Health in accordance with Chapter 6600 (relating to intermediate care facilities for persons with intellectual disability), providing a level of care specially designed to meet the needs of individuals who have intellectual disability, who require specialized health and rehabilitative services.

**Legal Guardian:** A person not affiliated with a provider agency who has legal standing to make decisions on behalf of a minor or adult (for example, a court-appointed guardian).

**Local Program:** The entity with which the AE contracts with to do independent monitoring within the county/joinder.

**Local Program Coordinator:** The person hired by the Local IM4Q Program board to direct its program.

**Major Concerns:** One of five types of abuse (physical dangers within a residential site/home or place of community activity, significant sanitation problems, evidence of physical abuse or neglect, evidence of psychological abuse, or evidence of a human rights violation), either witnessed by the monitoring team or expressed by the individual or others, that are to be immediately reported to the AE per policy established by the AE and Local Program.

**Major Concerns Policy:** The written policy between a Local Program and an AE which outlines the established steps to be taken and the timelines to follow by the Local Program in reporting major concerns to the AE.

**Medicaid Home and Community Based Services Waivers (HCBS):** A match of state and federal funding used to provide services to individuals enrolled in either the Consolidated or Person/Family-Directed Supports waiver.

**Money Follows the Person (MFP):** A program that provides individuals living in nursing facilities, ICF/IDs, and long-stay hospitals with informed choices and options about transitioning into a more integrated community setting.

**Monitoring Team:** A team of at least two individuals, comprised of people with disabilities, family members and interested others, who conduct interviews with the AE-designated sample of people receiving services/supports

**Monthly Reporting Form:** The Local Program Coordinator uses this document to capture monthly data on the number of surveys completed and the number of refusals encountered; copies are submitted to the AE and the appropriate ODP Regional Coordinator by the 10th day of each month.

**National Core Indicators (NCI):** A project focused on the quality of services received by people with intellectual disabilities and overseen by the Human Resources Institute in collaboration with the National Association of State Director of Developmental Disabilities Services (NASDDDS) Pennsylvania is a charter member and includes the NCI surveys as part of the IM4Q program.

**National Core Indicators Adult Consumer Survey (ACS):** The survey instrument used to conduct surveys for individuals identified in the NCI survey sample subset.

**National Core Indicators Adult Family Survey (AFS):** The survey created to by HSRI to request feedback from families whose relatives live at home with them concerning the services that their relatives receive. There is a separate, randomly-drawn statewide subset of individuals receiving services and ODP mails the survey to the primary contact as listed in HCSIS. Family members are not required to complete this survey.

**National Core Indicators Family/Guardian Survey (FGS):** The survey created to by HSRI to request feedback from families and guardians whose relatives do not live at home concerning the services that their relatives receive. There is a separate, randomly-drawn statewide subset of individuals receiving services and ODP mails the survey to the primary contact as listed in HCSIS. Family members are not required to complete this survey.

**National Core Indicators Pre-Survey Form and Background Information:** The beginning pages of the NCI Adult Consumer Survey, which contains the pre-survey and background information.

**Non-profit 501c3:** A legal status required of any entity contracted with an AE to provide independent monitoring services.

**ODP Regional Coordinator:** Staff assigned at each of the four ODP regional offices (Central, Northeast, Southeast, and Western) to perform duties related to IM4Q.

**Office of Developmental Programs (ODP):** The program office within the PA Department of Human Services which provides services to people with intellectual disabilities. It implements the Independent Monitoring for Quality and National Core Indicator projects.

**Older Adult Protective Services Act (OAPSA):** Legislative Act which protects older adults (60 and over) from abuse, neglect, exploitation, and abandonment.

**Online Data Entry Survey Application (ODESA):** The secure, web-based data entry system used by HSRI to collect states' data for the NCI surveys.

**Pennsylvania Developmental Disabilities Council (DDC):** A group comprised of people with disabilities, family members, advocates, and state department representatives created by the Developmental Disabilities Act to do capacity building, system change and advocacy on behalf of people with developmental disabilities and their families. The DDC is also represented on the IM4Q Statewide Steering Committee.

**Pennsylvania League:** Advocacy group represented on the Statewide Steering Committee: An advocacy group, typically of parents/family members of people living in state centers, who have a seat on the IM4Q Statewide Steering Committee.

**Person and Family Directed Support Waiver (P/FDS):** A federally-approved 1915(c) waiver program designed to help individuals with intellectual disabilities age 3 and older to live more independently in their homes and communities

**Pilot Survey:** A survey containing questions that target a specific group or purpose; they are only meant to be for short-term use.

**Program Reviews:** A meeting including the Local Program, AE, ODP Regional Coordinator, and Technical Advisors to discuss what is going well and what may need improvement in the IM4Q process.

**Protected Health Information (PHI):** Any information about health status, provision of health care, or payment for health care that can be linked to a specific individual.

**Quality Framework:** Guided by the values and principles of Everyday Lives, it measures, addresses and enhances quality of life, services and supports and organizational practices.

**Quality Management (QM) Strategy:** Description of the required level of quality and the approach to be used to ensure the specified standard of quality is met.

**Request for Proposals (RFP):** A document issued when an AE needs to contract with a new entity to provide IM4Q services; the new entity is chosen from the proposals received.

**Robert's Rules of Order:** Rules of conduct that provide for constructive and democratic meetings, to help the business of the assembled group.

**Self-Determination:** The concept promoting the right of individuals to determine the course of their lives, People need to be free to exercise this right. Self-determination includes the following nine guiding principles: choice, relationship, contribution and community, roles and responsibilities, control, dreams, dignity and respect, fiscal conservatism, and attitude.

**Self Determination Initiative of Pennsylvania:** An ODP-supported initiative

**Stakeholders:** A group of people, who, as a whole, are interested in or are affected by activities and decisions made to our intellectual disabilities service system.

**State Center Coordinator** – Person responsible for IM4Q responsibilities at all five state centers.

**State Center Lead:** ODP staff person assigned at each of the five state centers (Ebensburg, Hamburg, Polk, Selinsgrove, and White Haven) to complete IM4Q activities.

**State Center Supplement:** Supplement used with State Center residents who are not able to communicate answers to questions in Parts I and II of the IM4Q Survey.

**Statewide Steering Committee:** Committee responsible to review annual reports and to provide recommendations for system change to the ODP Deputy Secretary.

**Summary Reports:** A series of annual reports (statewide, county-specific, P/FDS, state center, and pilot) created by the contracted entity based on the data collected by local programs.

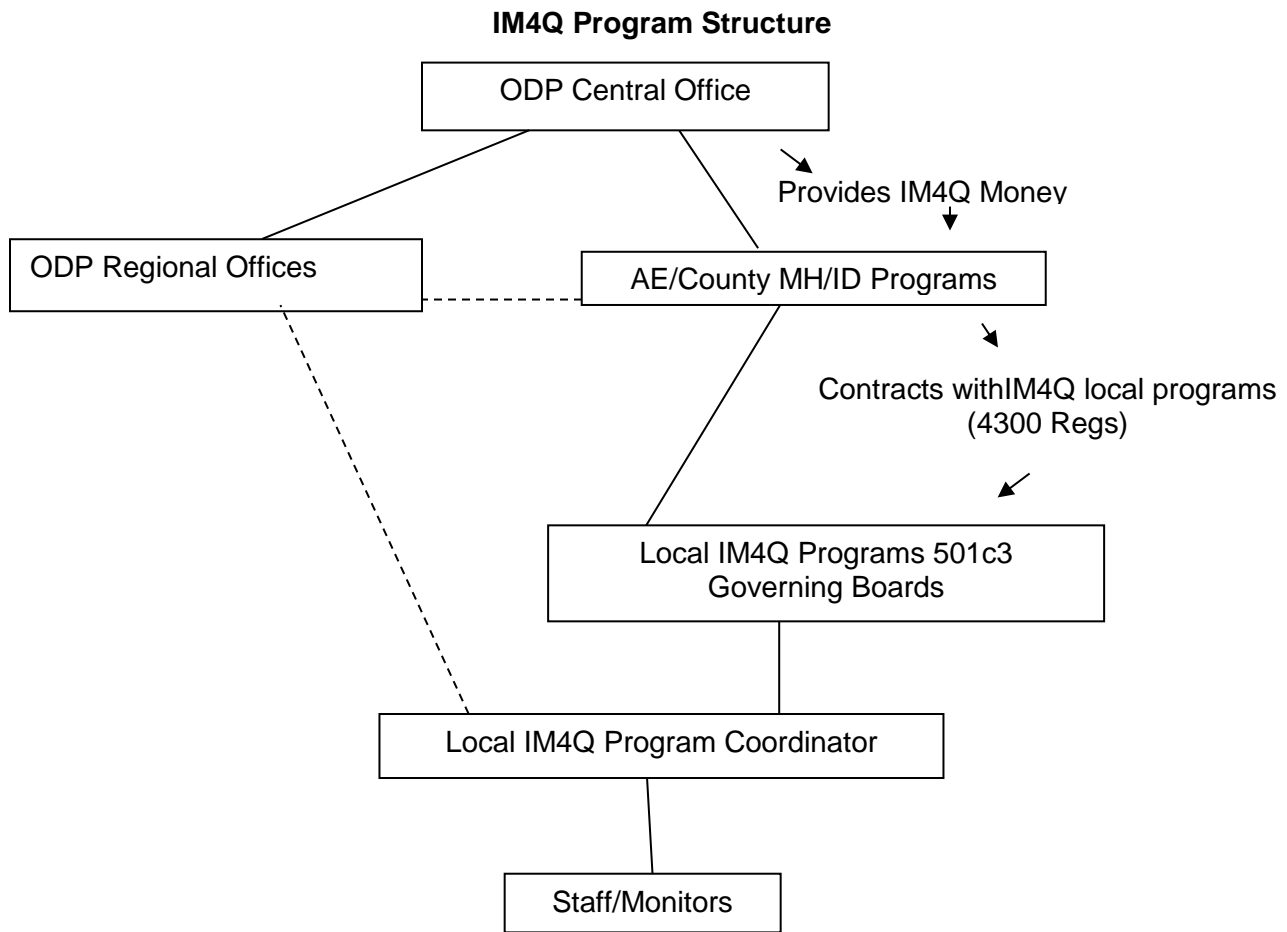
**Supports Coordinator (SC):** SCO employee whose primary functions are to locate, coordinate and monitor services provided to an individual.

**Supports Coordination Organization (SCO):** A provider qualified to deliver the services of locating, coordinating and monitoring services provided to an individual.

**Survey Sample Allocation:** The amount of funding provided to a Local Program based on the number of surveys to be completed and the rate per finalized survey, which are both determined by ODP.

**Technical Advisors (TAs):** Experts having a particular field of knowledge that are contracted to provide detailed information and advice to people working on IM4Q.

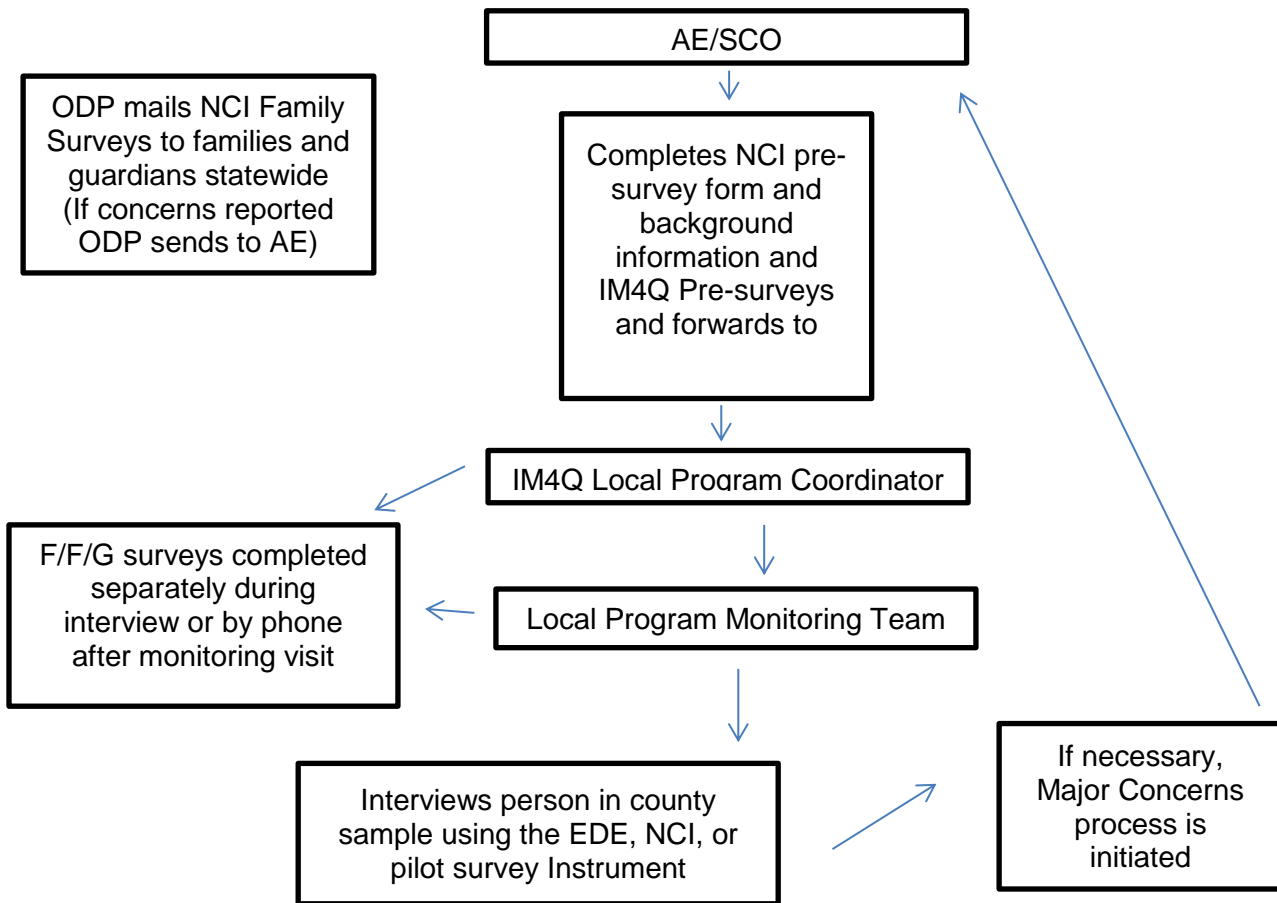
## Appendix B: IM4Q Program Structure and Processes



### Description for Flow Chart

The Central Office of ODP allocates IM4Q funding to Administrative Entities (AE). Each AE contracts with a Local Program that meets the requirements set forth in the IM4Q Manual and under the Chapter 4300 regulations to provide independent monitoring within their county (ies). The Local Program is governed by a 501c3 Board. Each Local Program's governing board hires a local IM4Q Program Coordinator. The Local Program Coordinator, with board approval, hires additional staff and monitors. Regional offices of ODP, which report directly to the Central Office, provide technical assistance and support to the AEs, as well as to the Local Program within their region.

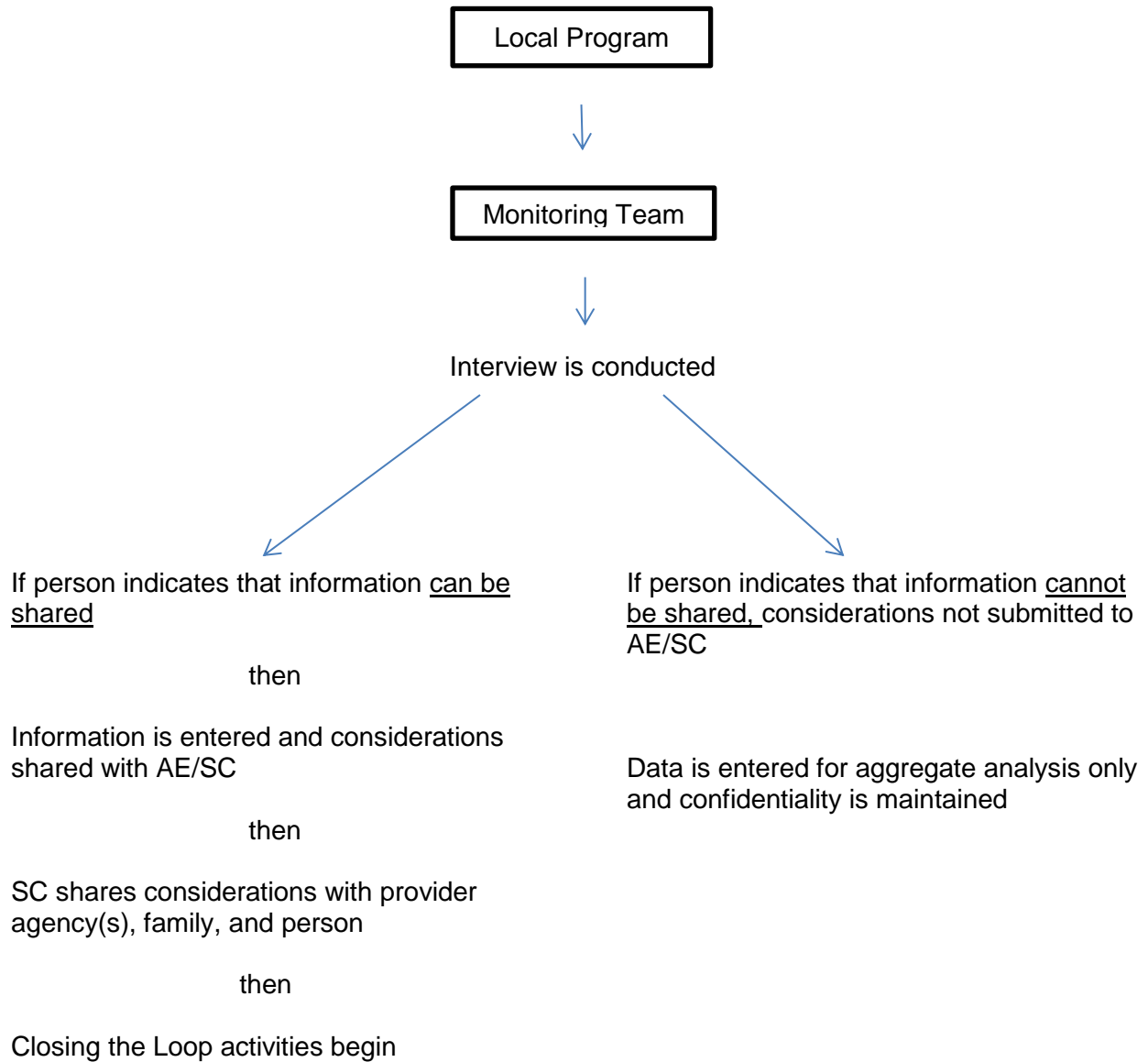
### IM4Q Data Collection Process



#### Description for Flow Chart

The AE completes the NCI pre-survey form and background information and IM4Q Pre-surveys and forwards these to the Local Program Coordinator. The Local Program Coordinator provides the pre-surveys to the monitoring teams. Each monitoring team interviews a person in the county sample using the EDE, NCI, or pilot survey instrument. If the opportunity arises during the visit, a member of the team may also complete a F/F/G survey with a family member or guardian; if not, then either a team member or the Local Program Coordinator can complete the survey by phone after the visit or by mail. A monitoring team, if necessary, initiates the Major Concerns process if concerns are identified during their visit. If the Major Concerns process is initiated, it is within the timeframe agreed upon by the Local Program and the AE in their Major Concerns policy. ODP mails out the NCI Family Surveys (Adult Family and Family Guardian) to family members and guardians based on a statewide sample.

## IM4Q Reporting to the AE



## Description of the Flow Chart

The Local Program assigns a monitoring team to interview a person from the AE sample list. Either of two paths can now occur: If the person interviewed decides that the information he/she is offering can be shared then the left side path is followed. Information is entered and considerations shared with the AE/SC. Next, the AE/SC shares the considerations with the provider agency, his/her family/guardianship/advocate, as well as the person interviewed. Finally, the Closing the Loop activities begin.

If the person interviewed decides that information from the interview cannot be shared, then the right side path is followed and no considerations are submitted by the monitoring team. However, the data collected during the interview does become part of the aggregate data entry process with the interviewed person's identity being maintained as confidential.

## IM4Q Data Entry Process

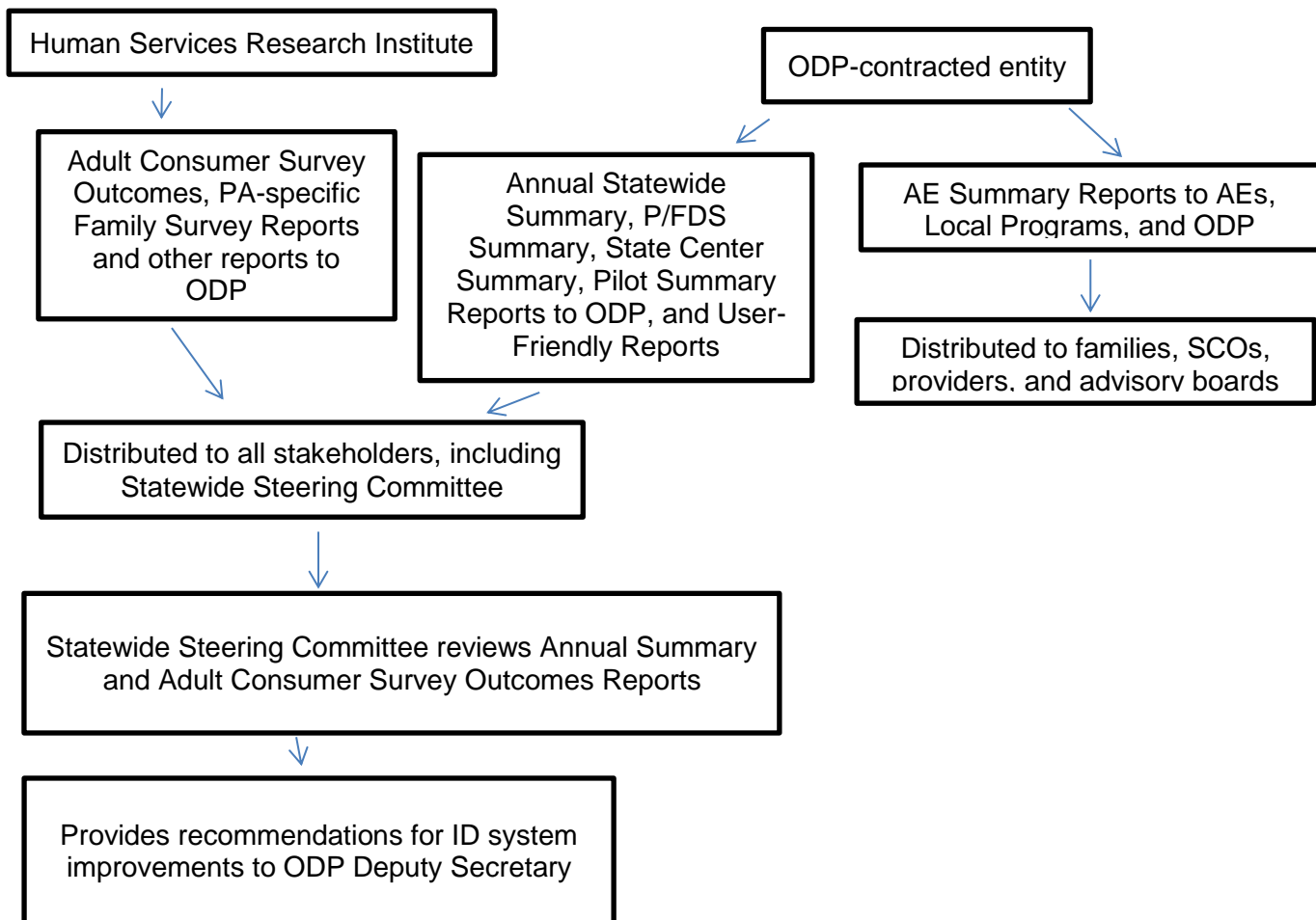
### Local Program:

- Enters all Consumer Pre-surveys into HCSIS
- Enters NCI Pre-survey and background information into ODESA
- Enters EDE and NCI Adult Consumer Surveys, and pilot surveys into ODESA
- Enters considerations into HCSIS

### ODP

- Enters NCI Adult Family and Family Guardian surveys into ODESA
- Sends IM4Q Pre-survey to contracted entity for analysis

## Issuance of Summary Reports and Recommendations



### Description of Flow Chart

The Human Services Research Institute (HSRI) sends ODP the Adult Consumer Survey Outcomes, PA-specific, and the Family Surveys and/or other reports.

The ODP-contracted data analysis entity sends AE summary reports to AEs, Local Programs, and ODP. The AEs and Local Programs will distribute the reports to individuals and families, SCOs, provider agencies, advisory boards and other stakeholders.

HSRI issue the Adult Consumer Survey and Family Surveys reports to ODP, which in turn distributes the reports to IM4Q stakeholders, including the Statewide Steering Committee. The Committee then develops recommendations for system improvements based on discussion of the NCI and contracted entity reports and submits them to the Deputy Secretary. ODP responds to the recommendations and its own analysis of the reports and then implements changes based on the analysis and recommendations.

## Appendix C: IM4Q–ISP Connection Practices

### Introduction

The Office of Developmental Programs convened the Independent Monitoring for Quality – Individual Support Plan (IM4Q-ISP) Connection Workgroup in March 2004 to address concerns and recommendations from the Statewide IM4Q Steering committee and other sources to improve the IM4Q ‘closing the loop’ process. The workgroup included representatives from various sectors of the IM4Q community: people with disabilities and family members, supports coordinators, researchers, county and local IM4Q Program staff, and ODP personnel. The recommendations of the workgroup also included input from County MH/ID Programs, Local IM4Q Programs, supports coordination agencies, advocacy associations, and groups such as the PAC and the ODP QM standing committees.

IM4Q is the statewide method that Pennsylvania has adopted to independently review the quality of life people experience in the intellectual disability service system. Focusing on individual satisfaction and outcomes, IM4Q is one of the few statewide programs of this kind in the country, pioneering community participation in the quality improvement process. Community participation is promoted by having persons with disabilities, family, and interested citizens as part of each IM4Q survey team. Such participation also helps to ensure the independence of the IM4Q survey process as team members are not affiliated with the services and support that the person receives.

Independent monitoring is one of a number of monitoring components within the intellectual disability service system. IM4Q adds a perspective on quality that does not focus on regulation, process, or compliance issues. IM4Q also helps to:

- Provide a more comprehensive view of quality by engaging people with disabilities, families and citizens as stakeholders in the lives of people in their community;
- Strengthen the advocacy base for people with disabilities in the community;
- Reinforce what human service professionals already know about the person, or raise issues that they would want to know; and
- Offer an additional safeguard for the health and well-being of individuals receiving services.

### Closing the Loop Process

The ‘closing the loop’ process refers to the practices used by County MH/ID Programs and Supports Coordination Organizations (SCOs), in collaboration with people with disabilities, family members, the provider community, and the local programs, to ensure that the considerations raised by IM4Q programs as a result of their survey interviews are being addressed by the County MH/ID Program and SCOs in a timely and effective way. The closing the loop process involves communication between the Local Program, the AE, and SCOs. This communication occurs within the structure provided by HCSIS.

As defined by the IM4Q Steering Committee, closing the loop means:

**Action taken that demonstrates to the satisfaction of the person with a disability and/or family that all considerations of the IM4Q Program have been taken seriously, have been resolved, or are in the process of being resolved. The source**

**of the consideration may include the person with a disability, family, staff person, friend, advocate, or IM4Q team. The status of resolution of considerations must be shared with the Local IM4Q Program. The loop is not closed until the individual or family says it is.**

In reviewing the various closing the loop processes used by the County and Local IM4Q Programs across the state, the workgroup noted variance in terms of meeting this definition. Areas of concern that the IM4Q Steering Committee and other stakeholders asked the committee to address include:

- Timeliness in addressing considerations;
- Redundancy and a lack of individualization in the content of considerations;
- Confusion on how individuals and families can access considerations and IM4Q reports;
- No clear linkage established between IM4Q considerations and HCSIS-based ISP and supports coordination monitoring practices;
- Lack of participation of people receiving services and families in the closing the loop process; and
- Inconsistency in how Local M4Q Programs are apprised of follow-up actions taken by the County.

To address the closing the loop issues that were raised, the IM4Q-ISP connection workgroup focused on development of a set of recommended practices. Implementation of these recommended practices are expected to have the following outcomes:

- Full participation of people with disabilities and family members;
- Linkage to the ISP team process in HCSIS, when appropriate;
- Linkage to supports coordination monitoring through HCSIS, when appropriate;
- IM4Q considerations are communicated, reviewed, and addressed in a timely, respectful, and accountable fashion;
- Affirm and strengthen the role of supports coordinators as the person's/family's main resource to improve the quality of services; and
- Provide another voice/perspective on the lives of people with disabilities that helps supports coordinators and providers improve outcomes for people.

These practices are recommended as guidelines for County, SCO and Local IM4Q Programs. Counties, SCOs and Local Programs are asked to review and compare their current procedures to the recommended practices and to make appropriate adjustments that will improve the IM4Q closing the loop process. Regional IM4Q Coordinators and Technical Advisors are available for support and clarification.

### **Recommended Closing the Loop Practices**

**The following are the work group's recommended practices to promote quality improvement within the IM4Q closing the loop process.**

<b>Planning, Orientation and Relationship Building</b>
<ol style="list-style-type: none"><li>1. The County, SCO and IM4Q Program <b>together</b> plan, implement and continuously improve the 'closing the loop process', as defined by the IM4Q Steering Committee (See page 1). Local IM4Q Boards are advised of these planning and implementation activities.</li><li>2. The closing the loop practices adopted by each County, SCO and Local IM4Q Program are written,</li></ol>

reviewed and modified to reflect changes over time. The practices include descriptions on:

- how people receiving services and families are involved in various phases of the process
- the role of the supports coordinator and other key County staff in processing IM4Q considerations and monitoring quality improvement actions
- how and when the ISP team is are involved in the closing the loop process

3. The County, SCO and IM4Q Program, **together and at least yearly**, orient and update supports coordinators, providers, ISP teams, people receiving services and families about:

- the value of IM4Q in the quality management framework
- the roles and responsibilities of key stakeholders
- written closing the loop practices
- how findings translate to improve services and support for the individuals and families being interviewed, as well as for the county service system.

4. County, SCO and IM4Q Program staff **together** maintain a positive working relationship among themselves and with providers, direct support professionals, the community at large, and people receiving services and families.

5. County registration workers explain IM4Q to the person/family at intake into the county program, including information for persons/families becoming a member of a survey team or local IM4Q board.

#### **Surveying People Receiving Services and Families**

1. The IM4Q program determines if a person, guardian or family member chooses to participate in a survey visit. If a supports coordinator or County representative is informed that a person or family does not want to participate, the County or supports coordinator contacts the IM4Q program to have this confirmed. ODP has clarified that determining choice of the person/family to participate in IM4Q is not a County or SCO function.

2. Before the survey visit is completed, the IM4Q monitoring team informs the person/family that:

- considerations including the person's concerns will be shared with the County if permission is granted by the individual
- the County or its' designee (typically the SCO) is expected to discuss the considerations with the person/family to decide on how best to address the issues
- the person has a right not to share this information. If there is a specific individual who the person does not want to share these results with, the IM4Q Program will make this known as part of the IM4Q considerations.

3. The person/family may have a copy of the blank survey form at the time of the interview if they request. (The survey must be returned to the team before the team leaves).

4. Considerations are developed by the team as soon as possible after the survey visit is completed. The process that the team uses in developing considerations assures that the team has the opportunity to review the person's and family responses to questions, other concerns expressed by respondents, and team observations.

5. Considerations developed by the team should be individualized, meaningful and important to the person's quality of life. They are based on the person's interview and team observations and are unique to the person's life.

#### **IM4Q Program Considerations to the County**

1. IM4Q team considerations are shared with the County within the agreed upon time frame that is satisfactory to the IM4Q Program, the County and SCO.

2. The IM4Q Program Coordinator or designee reviews and edits IM4Q team considerations to ensure that each final IM4Q Program consideration sent to the county is:
  - Concisely written in plain language
  - Constructive
  - Focused on the outcome that needs to be achieved or an issue that needs to be addressed, not on a particular service or method to be used in addressing the consideration.
  - Identified by the source or originator of the consideration (person receiving services, family, provider staff, or monitor).
  - Individualized based on the person's interview and team observations
  - Inclusive of any and all service related concerns expressed by the person or family during the interview even when the consideration is not related to the IM4Q questions.
3. The IM4Q Program advises the County on repeated and unresolved considerations from prior interviews if known.

#### **County Routing of IM4Q Considerations**

1. The County shares the IM4Q team considerations with the person's supports coordinator or other county designee who coordinates the county response with the person/family.
2. Upon receipt of the IM4Q consideration, the County or its designee communicates an initial response to the IM4Q Program that confirms receipt of the considerations and indicates first steps to address the considerations.
3. The supports coordinator/county designee communicates with the person, family and/or guardian to review and prioritize the considerations and determine how considerations will be addressed. This may include considerations where sources are from other people than the person being interviewed, including family, friends and staff.
4. The supports coordinator, in conjunction with the person/family/guardian, determines which considerations need to be addressed with the ISP team, recognizing that not all considerations need to take this route. IM4Q considerations are shared with the ISP team meeting at their next scheduled meeting unless the urgency of the consideration requires a special meeting to discuss. Either of the following two instances would require ISP team involvement:
  - A consideration would change the services and supports the individual receives
  - The person/family wants to review a consideration with the ISP team.
5. Considerations that are not routed to the ISP team are routed to other resources, as appropriate, or handled between the supports coordinator and the person/family.

#### **County Follow-up Actions**

1. Actions to address IM4Q considerations are implemented within a time frame established with the person and family and/or ISP team. The supports coordinator documents actions in the individual's record and discusses actions/ progress with the person/family and ISP team at scheduled meetings.
2. The supports coordinator monitors ISP-related actions with the ISP team using the HCSIS monitoring form, until all actions are completed to the satisfaction of the person/family.
3. The County IM4Q Coordinator or other County designee obtains information on the status of actions from the supports coordinator
4. The County IM4Q Coordinator or designee reviews follow-up actions with the IM4Q Program at regularly scheduled meetings, or through e-mail/phone contact and reports. When the IM4Q Program

brings a concern with follow-up action to the County’s attention, the County IM4Q Coordinator ensures that these concerns are addressed in a timely manner. The IM4Q Program informs the survey team about follow-up actions and considers the team’s opinion when meeting with the County

5. The County IM4Q Coordinator or designee informs the IM4Q Program when the loop is closed, per the definition provided by the IM4Q Steering Committee.

**County Program Review and Analysis**

1. The County and IM4Q program meet regularly to review considerations for trends and patterns for system quality improvement purposes.
2. The County and IM4Q Program, either individually or together, bring information on patterns and trends for system quality improvement to the attention of the County Administrator, IM4Q Board, and County MH/ID Advisory Board.
3. Where County based quality frameworks are developed, IM4Q patterns and trends for system quality improvement purposes are shared within the County’s quality framework.
4. The County and IM4Q Program agree on a process whereby local IM4Q teams follow-up with at least 10 percent of persons/families who have been surveyed to determine that the loop has been closed.

**Recommended Practices Promoting Self-Determination of People Receiving Services and Families**

One of the principles established by this work group is to promote the self-determination of people receiving services and families in the IM4Q process. The following is a summary of recommended closing the loop practices that reinforce this principle:

Planning, Orientation and Relationship Building	Surveying Individuals and Families	IM4Q Program Considerations to the County	County Routing of IM4Q Considerations	Follow up Action IM4Q Program
<p>Persons and families are informed about IM4Q at intake into the community intellectual disabilities program.</p> <p>The County, SCO and the IM4Q together orient people receiving services and families regarding IM4Q practices, roles and</p>	<p>The person/family are asked by the IM4Q program whether they want to participate in a survey</p> <p>The person is asked to give his/her permission before the results of the survey can be shared with the County and providers. Any specific persons who should not have access to survey findings are noted in the team’s</p>	<p>IM4Q considerations <b>MUST</b> include any and all issues raised by the person/family during the survey interview</p>	<p>The person/family meets with the supports coordinator or county representative to prioritize and determine the routing of considerations.</p> <p>Persons and families direct what and how actions are taken, in consultation with the supports coordinator.</p> <p>A consideration that</p>	<p>County actions to address considerations are shared with the person directly by the County or through the supports coordinator</p> <p>Persons and families review the status of actions to address IM4Q considerations with supports coordinator and/or ISP team</p> <p>Local IM4Q Programs follow-up with persons on the</p>

responsibilities  Relationship building around IM4Q involves families and people	considerations.  The person is advised that they will be consulted in the closing the loop process  Persons, families, and legal guardians may have a copy of the blank survey to review during the interview		the person/family wants brought to the ISP team is brought to the ISP team.	status of actions.
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**Individual/Family/Program Staff Access to IM4Q Surveys and IM4Q Considerations**

One of the tasks of this workgroup has been to review and recommend, in consultation with DHS legal counsel, the type of access individuals and families can have to the finalized surveys and considerations written by Local IM4Q Programs. The following are the workgroup’s recommendations in respect to this area:

1. People with disabilities who are interviewed can request a meeting with the Local IM4Q Program to review their IM4Q survey responses as recorded by the team. Access is limited to those sections of the EDE which the person responded to, or which others responded to on the person’s behalf. The person can also access the finalized Family/Friend/Guardian (F/F/G) Survey if the F/F/G respondent agrees. The person who was interviewed can request to review the finalized survey with or without a County representative being present. If discrepancies are discovered as a result of this meeting, the Local Program must amend the finalized IM4Q survey in ODESA as needed.
2. Family members, friends and guardians who complete the Family/Friend/Guardian portion of the EDE can request a meeting with the Local IM4Q Program to review the finalized F/F/G survey and considerations written by IM4Q Team with or without the County being present.
3. Parents of minors who are interviewed can also request a meeting to review the finalized EDE which is responded to by the person, staff or family members.
4. Legal guardians of the individual have the same rights as the individual to review the finalized Essential Data Elements. Parents of adults who are not legal guardians may only review the finalized survey results with an IM4Q Program representative with the approval of the person.
5. Written considerations from the Local IM4Q Program are intended for the County MH/ID Program. People receiving services, guardians and family members have access to these considerations through the closing the loop process established by the county program.
6. County MH/ID Program personnel, supports coordinators, ISP teams, provider agencies, and direct support professionals have no access to EDE survey results except as

provided to them through HCSIS user rights. Sharing individual results would violate the basic confidentiality of IM4Q. One exception to this rule is when, on request of the person/family/guardian, the County participates in a meeting with the Local IM4Q Program regarding the accuracy of IM4Q Program results.

7. IM4Q teams can share a copy of the blank EDE survey they are completing at the time of the survey with the person, family, or others participating in the survey. This can help people follow along. The blank surveys must be returned to the team after the interview is over and before the team leaves.

#### Questions and Additional Information

Questions, comments, and additional information regarding these practices can be addressed to the Regional IM4Q Coordinators.

## Appendix D: State Center Closing the Loop Process

### Introduction

IM4Q is the statewide system that the Commonwealth of Pennsylvania has adopted to independently review the quality of services and supports people receive in the intellectual disabilities services system. Focusing on individual satisfaction and outcomes, IM4Q is one of the few statewide programs of this kind in the country, pioneering community participation in the quality improvement process. Community participation is promoted by having persons with disabilities, family, and interested citizens as part of each IM4Q survey team. Such participation also helps to ensure the independence of the IM4Q survey process as team members are not affiliated with the services and support that the person receives.

Independent monitoring is one of a number of monitoring components within the intellectual disability service system. IM4Q adds a perspective on quality that does not focus on regulation, process, or compliance issues. IM4Q also helps to:

- Provide a more comprehensive view of quality by engaging people with disabilities, families and citizens as stakeholders in the lives of people in their community
- Strengthen the advocacy base for people with disabilities in the community
- Reinforce what human service professionals already know about the person, or raise issues that they would want to know
- Offer an additional safeguard for the health and well-being of individuals receiving services.

### Closing the Loop Process

The 'closing the loop' process refers to the practices used by a service provider, in collaboration with people with disabilities, family members, and the MH/ID program, to ensure that the considerations raised by IM4Q programs and data summary results generated as a result of their survey interviews are being addressed in a timely and effective way. As defined by the IM4Q Steering Committee, closing the loop means: **Action taken that demonstrates to the satisfaction of the person with a disability and/or family that all individual considerations of the IM4Q Program have been taken seriously, have been resolved, or are in the process of being resolved. The source of the consideration may include the person with a disability, family, staff person, friend, advocate, or IM4Q team. The status of resolution of considerations must be shared with the local IM4Q Program and the County MH/ID Program. The loop is not closed until the individual or family says it is closed. The IM4Q reports will be reviewed at the Center and Bureau levels, trends and patterns determined, quality improvement action recommendations made to the Center and Bureau Quality Improvement Councils, and quality improvement actions initiated and monitored.**

### Closing the Loop Practices

The following are the recommended practices to promote quality improvement within the IM4Q closing the loop process:

#### **A. Planning, Orientation and Relationship Building**

1. The State Center and IM4Q Program **together** plan, implement and continuously improve the 'closing the loop process'.
2. The closing the loop practices adopted by the Center and local IM4Q Program are written, reviewed and modified to reflect changes over time. The practices include descriptions on how people receiving services and families are involved in various phases of the process and the role of the QIDP, and ISP Teams in processing IM4Q considerations and monitoring quality improvement actions involved in the closing the loop process.

3. The Centers and IM4Q Program **together and at least yearly** orient and update QIDPs, ISP teams, people receiving services and families about:
  - The value of IM4Q in the quality management framework
  - The roles and responsibilities of key stakeholders
  - Written closing the loop practices
  - How findings translate to improve services and support for the individuals and families being interviewed.
4. The Center, AE, and IM4Q Program staff **together maintains** a positive working relationship among themselves and with the people receiving services and their families.
5. Center staff explains IM4Q to the person/family including information for persons/families becoming a member of an IM4Q program survey team or local IM4Q board.

#### **B. IM4Q Survey Process**

1. The IM4Q program determines whether a person, guardian, or family member chooses to participate in a survey visit. If the Center staff is informed that a person or family does not want to participate, the Center staff notifies the IM4Q program, who will still contact the individual/family to verify whether they want to participate. Effective in fiscal year 2006-07, all family notifications of IM4Q surveys will be made by the IM4Q Program with family information provided by the Center on the consumer pre-survey. The IM4Q Program will issue a standard letter prepared by ODP that explains the survey process and offers the family an opportunity to participate. The family member will be directed to the IM4Q Program for additional information if requested.
2. Before the survey visit is completed the IM4Q monitoring team informs the person/family that:
  - Considerations, including the person's concerns, will be shared with the Center and AE
  - The State Center is expected to discuss the considerations with the person/family to decide on how best to address the issues

The person has a right not to share this information. If there is a specific individual who the person does not want to share these results with, the IM4Q Program will make this known as part of the IM4Q considerations.
3. The person/family may have a copy of the blank survey form at the time of the interview if they request. (The survey must be returned to the team before the team leaves)
4. Considerations are developed by the IM4Q monitoring team as soon as possible after the survey visit is completed. The process that the team uses in developing considerations assures that the team has the opportunity to review the person's and family responses to questions, other concerns expressed by respondents, and team observations.

#### **C. IM4Q Survey Results Considerations**

1. The IM4Q Program Coordinator or designee reviews and edits IM4Q Team considerations to ensure that each final IM4Q Program consideration sent to the State Center and AE is:
  - Concisely written in plain language
  - Constructive
  - Focused on the outcome that needs to be achieved or an issue that needs to be addressed, not on a particular service or method to be used in addressing the consideration.
  - Identified by the source or originator of the consideration (person receiving services, family, provider staff, or monitor).
  - Individualized based on the person's interview and team observations
  - Inclusive of any and all service related concerns expressed by the person or family during the interview even when the consideration is not related to the IM4Q questions.

2. IM4Q Team considerations are shared with the State Center and AE via the AE IM4Q Coordinator or designee within the agreed upon time frame that is satisfactory to the IM4Q Program, the Center, and the AE.

3. The IM4Q Program advises the State Center and the AE on repeated and unresolved considerations from prior interviews if known.

**D. State Center Closing the Loop Process on Individual Considerations**

1. The Center shares the IM4Q Team individual considerations with the person's QIDP within 30 days of receipt, unless the urgency of the considerations require immediate attention.

2. Actions to address the IM4Q considerations are implemented within a time frame established with the person and/or family and the ISP team, but no longer than 90 days from the receipt of the considerations. The QIDP communicates with the person, family, and/or guardian to review and prioritize the considerations and determine how considerations will be addressed.

3. The QIDP, together with the person/family/guardian determine which considerations need be addressed with the ISP Team, recognizing that not all considerations need to take this route. IM4Q Considerations are shared at the next scheduled quarterly review meeting unless the urgency of the considerations requires a special meeting.

4. Either of the following two instances would require ISP team involvement:

- A consideration would change the services and supports the individual receives
- The person/family wants to review a consideration with the ISP team.

5. The QIDP monitors actions related to closing the loop actions/progress with the person, family, and ISP team at scheduled meetings.

6. The QIDP documents closing the loop actions in the person's record per the Center/ODP guidelines.

7. The Center reviews and monitors actions to address closing the loop IM4Q considerations with the IM4Q Program and the AE IM4Q Coordinator or designee such as the person's AE Supports Coordinator.

8. The State Center informs the IM4Q Program and the AE IM4Q Coordinator or designee such as the person's AE Supports Coordinator when the loop is closed on individual considerations along with forwarding a copy of the actions regarding the individual considerations.

9. The IM4Q Program will follow up with the individual or family to determine satisfaction with the closing the loop outcomes.

10. The AE SC or other designee of the County MH/ID Program/AE will plan to discuss IM4Q considerations and actions as part of the AE's annual visit to the individual at the Center.

**E. State Center and Bureau Review and Analysis of Center Considerations, Center Overall Summary Reports, and the IM4Q Data Reports**

1. Each Center's Quality of Life Committee reviews IM4Q individual considerations, Center overall summary reports, and IM4Q State Center Reports within 60 days of receipt/availability. The considerations, Center summary reports, and data are reviewed for trends and patterns for Center system quality improvement purposes.

2. Each Center's Quality of Life Committee presents the IM4Q reports findings (#1 above) of trends and patterns along with recommendations at the next Center's Quality Council meeting for review, input, and approval for quality of life improvement strategy planning.

3. The ODP Bureau IM4Q sub-committee reviews all 5 Centers IM4Q considerations, Center overall summary reports, and IM4Q State Center Reports within 60 days of receipt of all the reports. The considerations, Center overall summary reports, and data reports are reviewed for trends and patterns, along with recommendation for Bureau level system quality improvement purposes, and are presented at the next Bureau Quality of Life Committee meeting.
4. The Bureau Quality of Life Committee presents the IM4Q reports findings (#3 above) of trends and patterns from all 5 Centers along with recommendations at the next Bureau Quality Council meeting for review, input, and approval for quality of life improvement strategy planning.
5. The Bureau Quality of Life Committee monitors the effectiveness, results, and outcomes of strategies (#4 above) to improve/enhance quality of life at the Bureau system level.

## Appendix E: Requesting IM4Q Data, Analysis, and Reports

**Background:** Independent Monitoring for Quality (IM4Q) is a unique process and is one data source for quality improvement. IM4Q gathers and reports information about a number of critical areas from the consumer/families' vantage point.

Local Programs, as well as AEs, their Quality Councils, and provider agencies promote continuous quality improvement through the use of data such as IM4Q and may want to request IM4Q data, further analysis of IM4Q reports, and additional reports on specific data sets (e.g. a residential type, age-specific).

Local Programs, as well as AEs, their Quality Councils, and provider agencies go through a process of reviewing data to focus on areas that need improvement. Once areas are identified, they will often manage a plan-do-check-act quality improvement process, and report back on the success of these measures.

In order to utilize the IM4Q data as part of quality management at the Local Program, AE, their Quality Council, or provider agency levels, and to research possible trends for further analysis and planned improvement, a protocol to request data is necessary.

This is the protocol for Local Programs, as well as AEs, their Quality Councils, and provider agencies to use to request IM4Q data and acquire IM4Q reports that can support decisions about performance/outcome improvement.

### **Process:**

1. Local Programs, as well as AEs, their Quality Councils, and provider agencies review IM4Q reports and determine that further information is needed to adequately analyze the data. A request for IM4Q Reports or data is sent to the ODP Regional IM4Q Coordinator and the Technical Advisors. The request is submitted using the attached form.
2. Once the request is submitted, a phone conference will be held between the ODP contracted analyze entity and the requesting organization in order to confirm and to clarify report needs, format, etc.
3. The report generated by the ODP contracted entity will include an analysis, findings, and recommendations based on the data.
4. The ODP contracted entity Technical Advisor will complete the report and send the report with the completed form to the ODP Statewide and Regional Coordinators.

**IM4Q Data Request Form**

Local Program, AE, their Quality Council or Provider Agency Lead Name, contact information, email, phone number:

Date of Request:

Date Report is needed:

What is the business question(s) that this data is expected to address?

In general terms, what do you hope to learn from the report?

What action(s) you expect to implement based on this report?

**Data Requirements:**

IM4Q Report Year(s)/cycle(s):

IM4Q Focus Area Indicator

IM4Q question(s) [include question number(s)]

- 1.
- 2.
- 3.

**Comments**

**ODP Contracted entity to complete this section**

Report sent to:

Name, email, phone number:

Date:

Type of report provided:

## Appendix F: Request for Proposal to Provide IM4Q Services

### Introduction

This Administrative Entity of \_\_\_\_\_ has developed this request for proposals (RFP) to solicit the interest of any parties desiring to be considered to provide IM4Q services for the AE. Before responding to the exact criteria of the RFP, the interested party should get a copy of the latest Pennsylvania ODP *Independent Monitoring for Quality (IM4Q) Manual* from the AE IM4Q Coordinator. Also, you may want to confer with the AE IM4Q Coordinator, ODP Regional IM4Q Coordinator, and/or IM4Q Technical Advisors.

AE IM4Q Coordinator: \_\_\_\_\_  
Phone: \_\_\_\_\_ Email: \_\_\_\_\_

ODP Regional IMQ Coordinator: \_\_\_\_\_  
Phone: \_\_\_\_\_ Email: \_\_\_\_\_

### The criteria that are to be used to determine selection are as follows:

1. Interest in and clearly expressed rationale why independent monitoring is important
2. Must be a 501C3 organization or able to align itself to such an entity as the governing body
3. Will establish a governing board or advisory committee to an existing board that is 51% people with disabilities/family members
4. As an entity cannot provide direct, services/supports (e.g., residential. Vocational), to people with the intellectual disabilities Ability to quickly develop such a program
5. Independence from providers/AE structures
6. Availability of consumers/families/citizens to participate as monitors
7. Availability of consumers/families/citizens to undergo training
8. Structure/organization to operate a program
9. Lead person to be responsible for the program
10. Ability to participate in regional IM4Q quarterly meetings
11. Willingness to work with IM4Q ODP Regional IM4Q Coordinator, IM4Q AE Coordinator, IM4Q Technical Advisors, and other ODP staff
12. Ability to use an existing monitoring tool, the Essential Data Elements (EDE)
13. Capacity for internet transmission of data to a central point for analysis and dissemination
14. The effective utilization of the data collected in working with the AE to promote change
15. Suitability of proposed budget to conduct the project

If you have a serious interest in becoming one of the proposals selected, please send a letter of interest to the person listed at the end of the page, responding **briefly** to each of the fifteen above criteria. Your letter of interest will be reviewed and decisions will be made by the AE through consultation with ODP, the Technical Advisors and the Statewide IM4Q Steering Committee.

Send responses to: \_\_\_\_\_  
Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Respond By: \_\_\_\_\_

**Request for Proposal to Provide IM4Q Services**

**Use this chart to score a proposal using a scoring method of your choice**

CRITERIA	SCORE	COMMENTS
<p>1. The proposed monitoring entity is/will be incorporated and will enter into a contract with the county to conduct the monitoring.</p>	<p>_____</p>	
<p>2. The proposed monitoring entity is/will be independent of any provider of direct intellectual disabilities services in the county. Independent means having no contract to provide direct ID services (e.g. residential, day, or early intervention services) or in any way will be monitoring its own or any competitor's services.</p>	<p>_____</p>	
<p>3. The proposed monitoring entity is/will have a governing board composed of at least 51% of persons with a disability or family members of a person with a disability.</p>	<p>_____</p>	
<p>4. Of the 51% consumer/family membership on the governing board of the proposed monitoring entity, one half are/will be consumers capable of voicing their opinions, and one-half family members of people with intellectual disabilities.</p>	<p>_____</p>	
<p>5. Remaining members of the board are/will be other interested citizens who do not have a conflict of interest.</p>	<p>_____</p>	

6. The proposed monitoring entity has/will have a direct relationship with the County MH/ID Board.

\_\_\_\_\_

7. The proposed monitoring entity will submit all data directly to the contracting county and the statewide steering committee.

\_\_\_\_\_

8. Budgets submitted reflect reasonable and necessary costs of the project in the start-up year.

\_\_\_\_\_

9. Annualized budgets reflect reasonable and necessary costs for full-year operation.

\_\_\_\_\_

Reviewer: \_\_\_\_\_

County Reviewed: \_\_\_\_\_

**TOTAL  
SCORE:**

## Appendix G: Letter to Legal Guardian

Name  
Address  
Address

Date

Dear \_\_\_\_\_,

This letter is being sent to inform you, as legal guardian, that \_\_\_\_\_ has been randomly selected to participate in a survey with the Independent Monitoring for Quality program (IM4Q) in FY \_\_\_\_\_. IM4Q has been conducting surveys and reporting on trends to the Office of Developmental Programs (ODP) since 2000. This process allows ODP to measure people's quality of life and, to some extent, the quality of services delivered, and to make changes as a result of the information received through the survey process.

During the interview process, participants are asked questions by an IM4Q team of 2-3 IM4Q monitors about their lives and the services and supports they receive. Interviews are expected to be conducted within 1-2 hours and are held at the individual's place of residence or other place of their choosing. If it is indicated that a participant may not be able to verbally communicate clearly enough to answer all questions, the team will request that the people who know the participant the best be present at the interview for assistance. If you prefer, the interview can be scheduled for a time that you can also be present.

All interview participants are offered the opportunity to participate by the IM4Q Monitoring Team and may refuse at any time. Participants are informed of the process, including this notification to you, as well as the confidentiality of the survey. At times, issues are identified for improvement, and participants are asked if they will allow information gained from the process to be shared for this purpose.

The IM4Q interview process also includes an interview with family/friends/guardians. This interview will be scheduled as a telephone call after the team interview visit is concluded, or if you are there at the interview, may be completed at that time.

Enclosed is a brochure about IM4Q. Please contact me if you have any questions with this process or would like to be included in the survey interview.

Sincerely,

---

IM4Q Coordinator



## Appendix I: Sample Confidentiality Statement

(On agency letterhead)

(Agency name) staff has an obligation to those we interview to protect their identities and the information they provide to the Independent Monitoring for Quality (IM4Q) program. The identity of persons interviewed and the related data are to remain confidential. Removal of names or disclosure of identities and related information is strictly forbidden. The content of interviews is not to be discussed with anyone except program staff, and only as it is necessary to complete the assigned work. Additionally, sensitive interview information should not be discussed anywhere it could be overheard by persons who are not authorized to know this information.

As a member of the program personnel, monitoring team, or data entry staff of the IM4Q program, I agree that I will protect the confidentiality of all information identifiable to a private person that is collected in the conduct of my work for the IM4Q program.

I agree that I shall not discuss any identifiable information that I may learn of during the course of my employment with anyone other than project staff members who have a need to know this information.

I agree to follow the procedures established by (agency name) to prevent unauthorized access to information identifiable to a private person.

I certify that I have been informed that (agency name), which is being funded in whole or in part by the Office of Developmental Programs and that I, as a member of the IM4Q program's personnel, monitoring team, or data entry staff, am governed by privacy stipulations as well.

I understand that my signing this agreement is a condition of my employment as part of (agency name)'s IM4Q program's personnel, monitoring team, or data entry staff.

By signing this statement, I am acknowledging that I understand the rules surrounding the protection of confidential information.

Full Legal Name (please print): \_\_\_\_\_

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date