



**Community Health Records:**  
Sharing Information, Empowering People

September 2009

## Introduction

“All people, regardless of disability, deserve the opportunity for a full life in their community where they can live, learn, work, and play alongside each other through all stages of life. People with mental retardation and related developmental disabilities<sup>1</sup> need varying degrees of support to reach personal goals and establish a sense of satisfaction with their lives.”

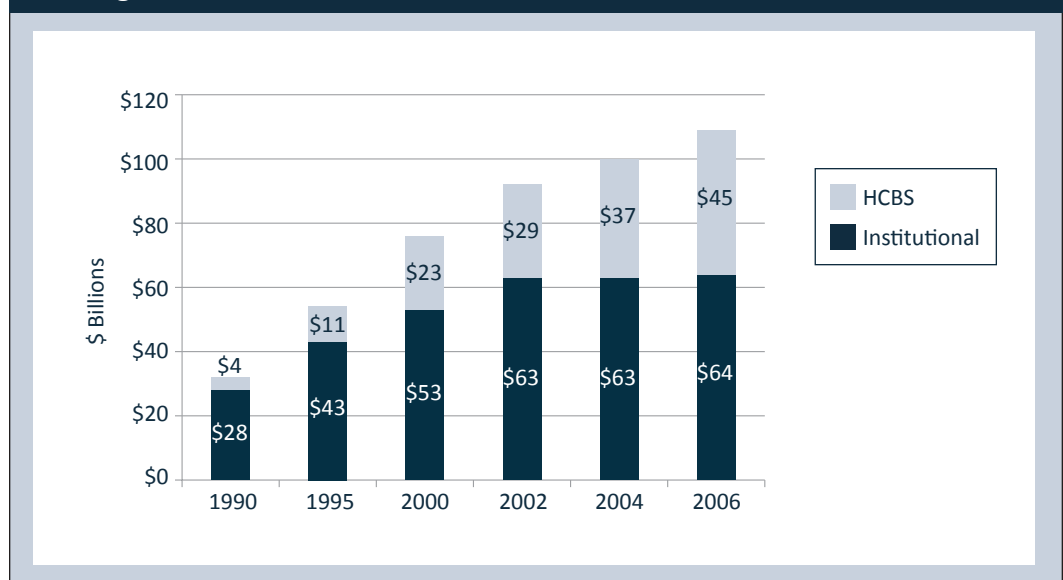
— *Policy Statement, Arc of the United States*

Community integration for people with intellectual or developmental disabilities (ID/DD) has been significantly advanced by the ability of states to use Medicaid funding for home and community-based services. Figure 1 presents the growth in funding for both long term care services and home and community-based services (HCBS). As this chart indicates, the percentage of those services delivered in community settings has expanded rapidly from 13% in 1990 to 41% in 2006, when over \$45 billion in long term care funding was directed to HCBS for people with ID/DD and related disorders.

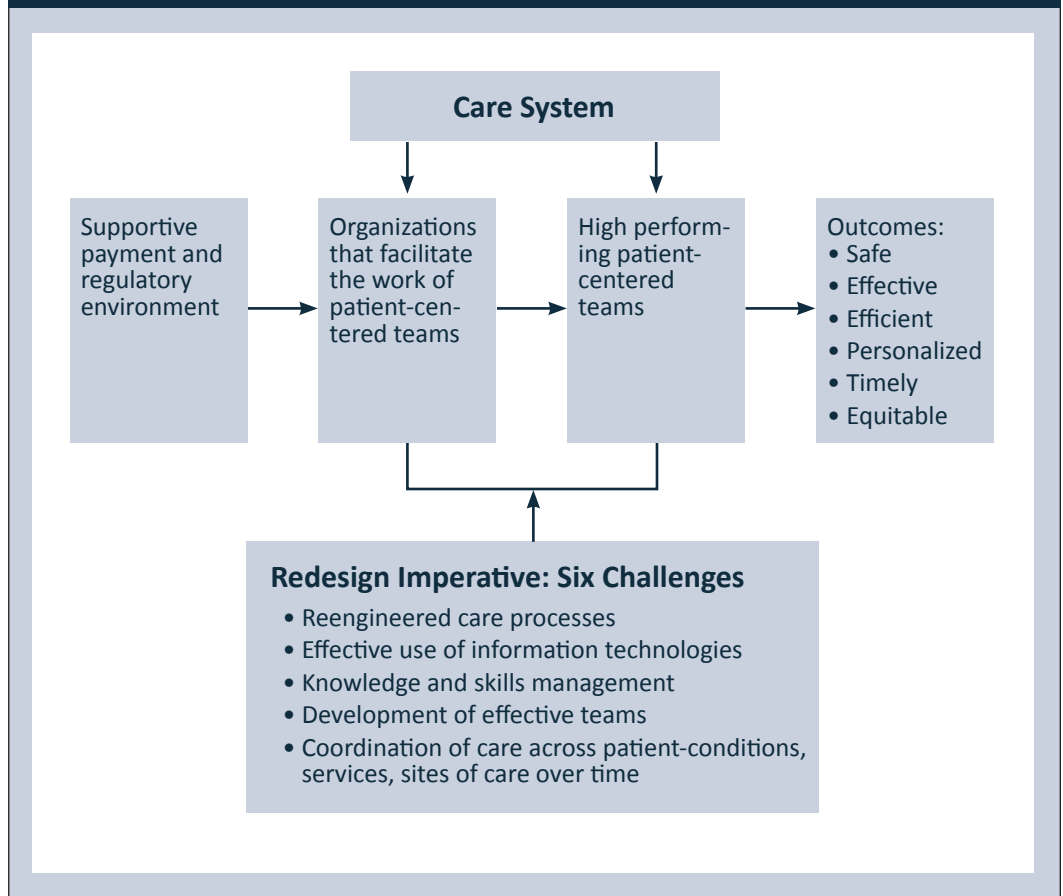
Increased interest in the delivery of services and supports that promote “real homes, real friends, real jobs, and real lives”<sup>3</sup> for people with ID/DD has been accompanied by challenges to the health and safety of individuals in the community. A key premise of community integration is the ability of people to live independently and make choices for themselves about the services and supports they receive – choices that are based on accessible, timely, and accurate information about their functional requirements and individual preferences.

Information about the services and supports availability and utilization of existing and emerging consumer needs, and opportunities to coordinate services is essential to the creation of safe and healthy communities for people with developmental disabilities.

**Figure 1. Increase in National Spending on Long Term Services and Share of Funding for HCBS<sup>2</sup>**



**Figure 2. The IOM Framework for Change**



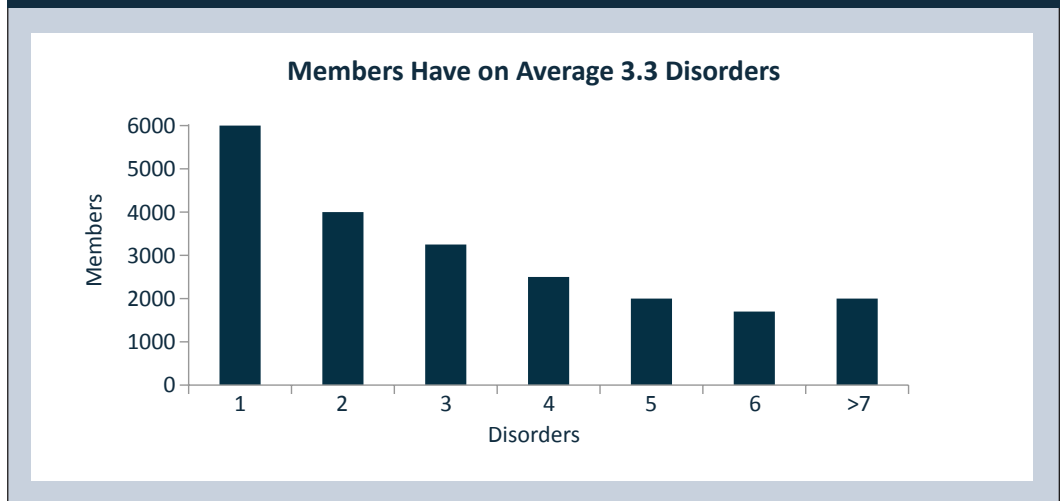
Since the publication of the Institute of Medicine (2001) report, “Crossing the Quality Chasm: A New Health System for the 21st Century,” significant national attention has been given to the importance of health information technology in the effort to improve quality and reduce medical errors. In this report the Institute of Medicine (IOM) described a framework for change, illustrated in Figure 2.

The IOM articulated six challenges to achieve a safer and higher quality system of care. One challenge expressly addresses the use of information technology; however, *all* challenges would be more successfully addressed in the context of information technology.

In addition to its place in the national dialogue on healthcare quality, implementation of information technology has also been associated with cost containment and consumer safety. The IOM’s vision was directed at the healthcare system but its message is no less compelling for the developmental disability community.

The Office of the National Coordinator for Health Information Technology noted that the application of health information technology can reduce costs as much as 20% while decreasing errors associated with care and improving coordination of services.<sup>4</sup>

**Figure 3. Comorbidities Among CCM-Eligible Members**



A major focus of national discussion has been on the implementation of electronic health records (EHR) in the hospital and physician office settings, and their use in the treatment of “patients.” People with developmental disabilities – while not patients – share important similarities with people using healthcare services in terms of the benefits offered by information technology:

- Ability of service teams to access a single source of information about the person.
- Transparency of information across stakeholders, including providers, state agencies, and the people themselves.
- Access to information difficult to obtain by consumers, such as administrative data about reimbursements to providers.
- Standardized formats for presenting information to consumers and providers.
- Linking consumer-level information to educational resources and delivering these resources in a user-friendly, organized format.

Additionally, individuals with ID/DD may also have complex and chronic health conditions that should be effectively addressed with the same concern for individual choice that is a central component of person-centered service delivery.

Information technology holds great promise to improve the quality and effectiveness of home and community-based settings, even though the challenges to successful adoption may be greater than those facing healthcare providers. In this paper we introduce the concept of a “community health record” to characterize the information technology approach needed to support a healthy and safe community for people with developmental disabilities and promote their independence and inclusion in the life of the community in meaningful ways.

## Community Health Records

An electronic medical record (EMR) is a healthcare/service record that is owned by a provider with specific information about healthcare encounters. An EMR is provider-centered. By contrast, an electronic health record (EHR) integrates electronic medical records into a consolidated record of health services at the consumer level, is owned by the consumer, and is accessed by the consumer and other stakeholders and providers to support the consumer's utilization of healthcare services. It is a person-centered record. The Community Health Record (CHR) extends the concept of an EHR out of the healthcare setting and into the community, incorporating non-healthcare services and supports that consumers use in home and community-based settings.

A Community Health Record consolidates reimbursed services into a person-centered database – integrating healthcare, services and supports (such as supported employment), pharmacy utilization, and the individual service plan into an electronic record that can be accessed by purchasers, providers, and most importantly, by consumers and family members. Secure, electronic Community Health Records represent a significant advancement in the effort to promote dignity, independence, and community inclusion for people with developmental disabilities.

### Advantages of Community Health Records

The Community Health Record, with its integration of provider-based, community-based, and home-based healthcare and social services and support, provides many advantages to developmental disability stakeholders:

- **One source for information about the person.** The fabric of services and supports that people with developmental disabilities need to live successfully in the community is often woven from a network of individuals and small provider agencies. A single source that brings together information about these diverse resources enables the individual, family members, and purchasers to quickly identify duplications and gaps, increasing the appropriate use of resources and removing wasteful spending from the system.
- **Identification of quality and safety concerns.** Consumers, advocates, and others have long expressed concern, for example, over the prescription of certain medications for individuals with developmental disabilities, and the extent to which individuals receiving these medications also receive appropriate clinical supervision of prescription regimens. The Community Health Record integrates pharmacy data with healthcare claims to identify specific prescriptions and the presence of appropriate clinical supervision validated by consumers, families, and agencies.
- **Reduction of fraud, waste, and abuse.** Inappropriate billing and treatment patterns flourish in an environment where information is fragmented and uncoordinated. The process of creating a Community Health Record validates, organizes, and integrates disparate sources of information such that two critical processes can be accomplished – individual consumers can verify their own records of services and supports, and analysis of the linked data can be conducted to identify cross-consumer patterns.

- **Transparency of Individual Service Plans (ISPs).** Developmental Disability agencies have worked diligently with advocates, consumers, and family members to promote self-direction in the development of ISPs, which historically were too often developed by others with little or no input from consumers and their family members. In the context of a Community Health Record, the ISP is a shared document that can be viewed by individuals, family members, providers, and purchasers at the same time – promoting communication and shared responsibility for plan development.
- **Reduction of administrative burden to purchasing agencies.** Agencies supervising public programs have responsibilities to ensure that program funds are used to achieve program goals at the system and individual level, yet they are often without the information tools needed to easily identify best practices or opportunities for improvement. The Community Health Record and its component datasets provide the ability to examine an individual’s record and create reports that facilitate identification of trends and patterns.
- **Support for consumer-directed options.** As the ability of people to manage their own funding increases, the Community Health Record supports financial planning, accountability, and independence in a secure environment. It also promotes consumer empowerment by delivering the information people need to manage resources effectively and participate in the planning process with their care team.

## APS CareConnection® — A Community Health Record System

APS Healthcare, Inc. is a leading provider of quality evaluation, management and improvement services in the field of public sector healthcare and social services. With over 30 programs in 20 states and Puerto Rico, APS supports state Medicaid and other agencies that serve over 16 million Medicaid recipients. APS CareConnection® is the proprietary data system developed by APS to address information management and knowledge sharing demands common to public sector programs.

With modules to support consumer-directed budgeting, prior authorization and concurrent review, as well as chronic care management, APS CareConnection® is a secure, HIPAA-compliant data system that is accessed by APS employees, providers, purchasers, and consumers in 13 states.

This web-based application has been designed to accommodate a variety of Internet access speeds, making it appropriate for small and rural states where high speed internet may not be readily available outside of city areas. As a Community Health Record, APS CareConnection® addresses the following requirements for CHRs:

- HIPAA compliant views organized specifically for purchasers, consumers, providers, and review agencies such as APS.
- Data integration of healthcare, community, and pharmacy claims into a comprehensive, person-centered database.
- Alerts, messages, and issue identification that promote communication between providers and consumers, promotes consumer safety, and enhances documentation of consumer questions and concerns.
- Inclusion of guidelines, publications, and web links to promote the adoption of evidence-based practices among providers.

- Availability of user-friendly, culturally appropriate tips and tools to inform consumers about choices for themselves and others.
- Transparency of ISPs and other consumer documents to promote a shared understanding of consumer goals and interests, and shared accountability for realizing personal goals and objectives.

## Summary

The ability of information technology to support valuable goals for individuals with developmental disabilities is beginning to receive serious consideration for home and community-based services. A Community Health Record meets the knowledge-sharing and data integration needs of the developmental disabilities field by consolidating waiver services, pharmacy, healthcare, and other information into a person-centered database that can be accessed by many stakeholders.

While there are many challenges to the successful adoption of CHRs, opportunities to significantly enhance consumer independence and system accountability make it worthwhile to pursue the implementation of such a system. APS CareConnection® represents a robust Community Health Record system available to developmental disability agencies and their stakeholders to meet program goals.

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## Notes

1 "People with mental retardation and related developmental disabilities" refers to our constituency, *i.e.*, those defined by the AAIDD classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

2 Kaiser Commission on Medicaid and the Uninsured. *As Tough Times Wane, States Act to Improve Medicaid Coverage and Quality: Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2007 and 2008.*

3 Reinventing Quality 2008 Brochure. Sponsored by the National Association of State Directors of Developmental Disability Services and the National Leadership Consortium on Developmental Disabilities at the University of Delaware. Available: [www.reinventingquality.org](http://www.reinventingquality.org). Accessed: June 29, 2008.

4 Available URL: <http://www.hhs.gov/healthit/valueHIT.html>. Accessed August 31, 2006