

KANSAS SYSTEM TRANSFORMATION TASK 2 TEAM SELF DIRECTION RESEARCH PROJECT

EXECUTIVE SUMMARY

I. PROJECT SUMMARY

The State of Kansas has offered self-directed Home and Community-based Services (HCBS) to individuals with disabilities and chronic conditions for a number of years. The Department of Social and Rehabilitation Services (SRS), Division of Disability and Behavioral Health Services (DBHS) offers self-directed services to eligible individuals through four Medicaid §1915(c) HCBS waivers: Physically Disabled (PD), Traumatic Brain Injury (TBI), Mental Retardation and Developmental Disabilities (MR/DD), and Technology Assistance (TA). The Division also was a recipient of a Robert Wood Johnson Foundation Self Determination Grant under which it implemented HCBS using a self determination approach for individuals with MR/DD from 1996-2000.

The Kansas Department on Aging (KDOA) offers self-directed services to elders through its Medicaid §1915(c) HCBS Frail Elderly (FE) Waiver. Kansas Health Policy Authority (KHPA), the Medicaid Single State Medicaid Agency in Kansas, offers self-directed services through a §1937 Benchmark Benefit Package for individuals enrolled in the *WORK* Program. Kansas also was awarded an FY'06 CMS Systems Transformation Grant which included the implementation of Goal 2: *Increased Choice and Control: Development /Enhancement of Self-Directed Service Delivery System*.

In August 2008, the Kansas Department of Social and Rehabilitation Services (SRS) executed a consulting contract with Dr. Susan A. Flanagan, of the Westchester Consulting Group in Washington, DC, to collect, analyze and report on credible information and recommendations that will assist the State in enhancing self-directed services and related supports (Financial Management Services or FMS) currently provided under *Participant-Employer Authority* and examining the feasibility of implementing the additional self-directed options through the implementation of *Participant-Budget Authority*. This research project has been conducted in association with the Task 2 Team of the State's FY'06 CMS Systems Transformation Grant.

The research project consisted of a number of tasks which included:

- Conducting an environmental scan of the five Kansas Medicaid §1915(c) HCBS waivers that offer self-directed services (PD, FE, MR/DD, TBI, and TA) and the *WORK* Program. The environmental scan examined the current implementation of self-directed services and Financial Management Services (FMS) using Participant-Employer Authority, and related supports in Kansas, and the feasibility of implementing Participant-Budget Authority in the future.

- Reviewing CMS §1915(c) HCBS waiver application, instructions and guidance that apply to the implementation of self-directed services and FMS under Participant Employer and Participant-Budget Authority;
- Identifying selected states' lessons learned and promising practices related to self-directed service programs and FMS implemented under Participant-Employer and Participant-Budget Authority; and
- Preparing a report that summarizes the finding of the environmental scan; CMS §1915(c) HCBS waiver application, instructions and guidance; and selected states' lessons learned and promising practices; and provides recommendations for enhancing the provision of self-directed services and FMS under Participant-Employer Authority in Kansas and the possible implementation of Participant-Budget Authority in future Kansas §1915(c) HCBS waiver renewals.

II. OVERVIEW OF SELF-DIRECTION

Over the past 20 years, there has been a tremendous growth in interest and implementation of publicly-funded self-determination and self-directed care programs for persons of all ages with disabilities and chronic conditions (Simon-Rusinowitz, Bochiak, Mahoney and Hecht, 2000; Simon-Rusinowitz and Hofland, 1993; Meiners, Mahoney, and Shoop, 2002; Doty and Flanagan, 2002; AARP, 2006; Dulio, Perry, Claypool and O'Malley, 2008). Self-directed care – also called consumer-directed or participant-directed care – is based on a belief that individuals with disabilities know best how to meet their needs and should be empowered to have greater autonomy and control over the home and community-based services (HCBS) they receive; and, the individuals who provide them (AARP, 2006, Squillace and Firman, 2001; Doty and Flanagan, 2002).

At a minimum, the self-directed care model allows individuals with disabilities of all ages, or others, such as family members acting as the individuals' representatives, to select and dismiss their HCBS workers. These workers are generally referred to as personal assistance, aides, attendants or support workers, who are paid to provide activities and instrumental activities of daily living and other disability-related supportive services (Doty and Flanagan, 2002). When individuals direct and control the selection, supervision, and discharge of their HCBS worker, the Centers for Medicare and Medicaid Services (CMS) refer to this participant direction opportunity as *Participant- Employer Authority*. When individuals are allowed to have and manage an individual budget and purchase approved goods and services that decrease their dependence on hands-on care and increase their independence, CMS refers to this participant direction opportunity as *Participant –Budget Authority* (CMS §1915(c) *Instructions, Technical Guide & Review Criteria*, Version 3.5).

The majority of Medicaid-funded self-directed service programs operate under §1915(c) HCBS waivers. The Deficit Reduction Act (DRA) of 2005 allows states to include the self-directed personal assistance service (PAS) option in their state home and