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Introduction

Each day the number of individuals receiving supported employment, long-term support, or extended services increases. Unfortunately, much of our attention has focused on the front end of supported employment. That is, making supported employment services available to the thousands of persons with disabilities who are asking for it. While attention to these front-end tasks must continue, without increased attention to long-term support services, supported employment cannot survive.

The demonstrated success of supported employment has challenged the human service field to alter some aspects of service provision by incorporating the techniques of supported employment (e.g. intensive one-on-one training using behavioral techniques and facilitating natural supports, and providing or facilitating consistent long-term services and supports), as well as, incorporating the values that underpin supported employment (e.g. consumer choice, integration and flexible/natural support). The result of this incorporation has spawned additional initiatives such as supported living arrangements and supported recreation. While imitation is highly complimentary, many leaders in supported employment believe that our delay in adequately acknowledging and dealing with issues related to ensuring the availability of quality, coordinated long-term supports and services has led to a supported employment system infrastructure that is not as stable as required (Albin, Slovic and Mank, this issue; Griffin, Test, Dalton and Wood, this issue; Wehman and Kregel, 1994).

Advocates of supported employment are to be

somewhat congratulated for the steps taken to foster integration and partnership of this concept into other service systems. The political climate in Washington, however, is visibly unstable as we witness congressional battling to disband unfunded mandates, cut spending, and create mass reform within our welfare and healthcare systems. While supported employment has, for over a decade, done exceedingly well in both democratic and republican climates, it will not, until now, undergo such scrutiny along with its counterparts.

It is clear that we have not given sufficient attention to the very cornerstone of supported employment — long-term support. The intent and organization of this special edition on long-term support is to unabashedly examine long-term support and its parameters, acknowledge the difficult climate in which we struggle to excel, dissect the funding infrastructure that underpins our long-term support system, offer clear (and often under-utilized) funding alternatives, and finally promote quality and integrity of long-term services and supports through showing how ancillary (but critical) resources can be used.

Overview of long-term services and support issues

In the first manuscript, Griffin, Test, Dalton and Wood, who work collaboratively from two University of North Carolina campuses and from within their home communities, present an overview of a number of current long-term support issues related to supported employment and suggest areas for further consideration for improving the service provision. In the second manuscript, Test, Dalton, Beroth and Dotson pro-

vide the results of a demographic study conducted in North Carolina that was designed to provide a 'snapshot' of the lives of people with developmental disabilities in the long-term support phase of supported employment. Data were gathered from a variety of sources including the supported employee, parents/family, support staff, and employers. Results were used to describe the typical/average North Carolinian in supported employment.

Financial resources for long-term services and support

These two introductory pieces are followed by three articles describing various 'resources for providing long-term support services.' First, Joyce Albin Dean, Roz Slovic and David Mank — all of whom are from the University of Oregon — review the original development of a funding model for supported employment and describe why that model does not meet current needs. They then provide a list of creative, alternative strategies to encourage individuals with disabilities, advocates, funders, service providers, and others to seek out new possibilities for support. They suggest that new coalitions are needed that can lead to redefinition of roles, new partnerships, shared resources, reduction in duplication of services, and increased incentives for using existing resources differently.

Second, Robert Gettings of the National Association of State Directors of Developmental Disability Services updates us on the current status of the Home and Community-Based (HCB) Medicaid waiver and the use of its supported employment provisions, outlining major factors involved in its low utilization including: (a) lack of prior institutionalization in the histories of two-thirds of waiver participants, (b) the tendency of states to limit eligibility to individuals with the most extensive support and service needs, (c) delays in implementing the supported employment coverage option, (d) the fact that eligibility is limited to individuals who would otherwise require institutional care, (e) the fact that supported employment is defined as a sub-element of habilitation services and applicable only to Waiver participants with developmental disabilities, and (f) the

general barriers to expanding supported employment services, particularly to individuals with severe disabilities. Unresolved federal policy issues are discussed and information on obtaining a more complete report, are also included. This piece once again reminds us of the importance of being ever-vigilant of the legislative process — especially in this tumultuous political climate.

Third, Tom Emmons, who directs a privately held Denver-based corporation that assists persons with disabilities in creating effective PASS plans, provides readers with three excellent case studies that demonstrate the range of options possible when using PASS plans to pay for long-term services and supports. Tom's article also reminds us that PASS plans are an underused source, in that only a small fraction of people eligible for the program actually take advantage of the PASS plan option.

Resources for sustained, consumer-directed support

Julie Racino, from Syracuse-based Community and Policy Studies, suggests that Personal Assistance Services (PAS) have the potential to translate the ADA into reality for millions of citizens with disabilities. While PAS has gained recognition and use as a support option for persons with physical disabilities, other disability groups have not yet embraced the option.

Finally, Kay Holjes, Charlie Bullock (both from North Carolina), and Michael Mahon (from Winnipeg, Manitoba) remind us that the goal of work is to enjoy its rewards. The effects of long-term services and supports should extend beyond the workplace to community participation. They describe, from practitioner and academician perspectives, how the implementation of a leisure education program can support both the goal of employment as well as the broader purpose of community participation and enjoyment. Key elements of the leisure education program are described, with examples of how the elements were incorporated into a supported employment program.

In addition to the more traditionally written articles in this special edition, we have encouraged the invited authors to submit shorter, less formal, but provocative pieces that provide obser-

vation and insight into several of the critical issues raised. Issues such as true customer-driven service provision, day service conversion, creative financing mechanisms, and staff/parent/consumer training can not be ignored if we are to be successful in our goal of ensuring the availability of quality long-term supports and services.

Combined, we believe that these articles provide an excellent summary of the current status and future challenges surrounding the long-term support needs of both persons in, and in the field of, supported employment. We believe that the essence of this special edition will encourage readers to facilitate creative risk-taking that leads to customer-driven supports and services. We hope you agree.

Acknowledgement

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