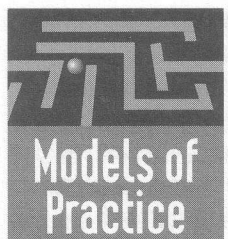


## A Paradigm Shift for Adult Day Services

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**P**lacing rings on sticks, beads on strings and pegs on boards describes the day of many participants in classic Adult Day or Adult Habilitation programs. Their historical focus on skill acquisition, leisure, academics, activities of daily living and community outings is in need of transformation. Best practice recognizes that people grow and develop and become more independent as a result of participating in meaningful life activities, not pretend life activities. The question becomes this: how do

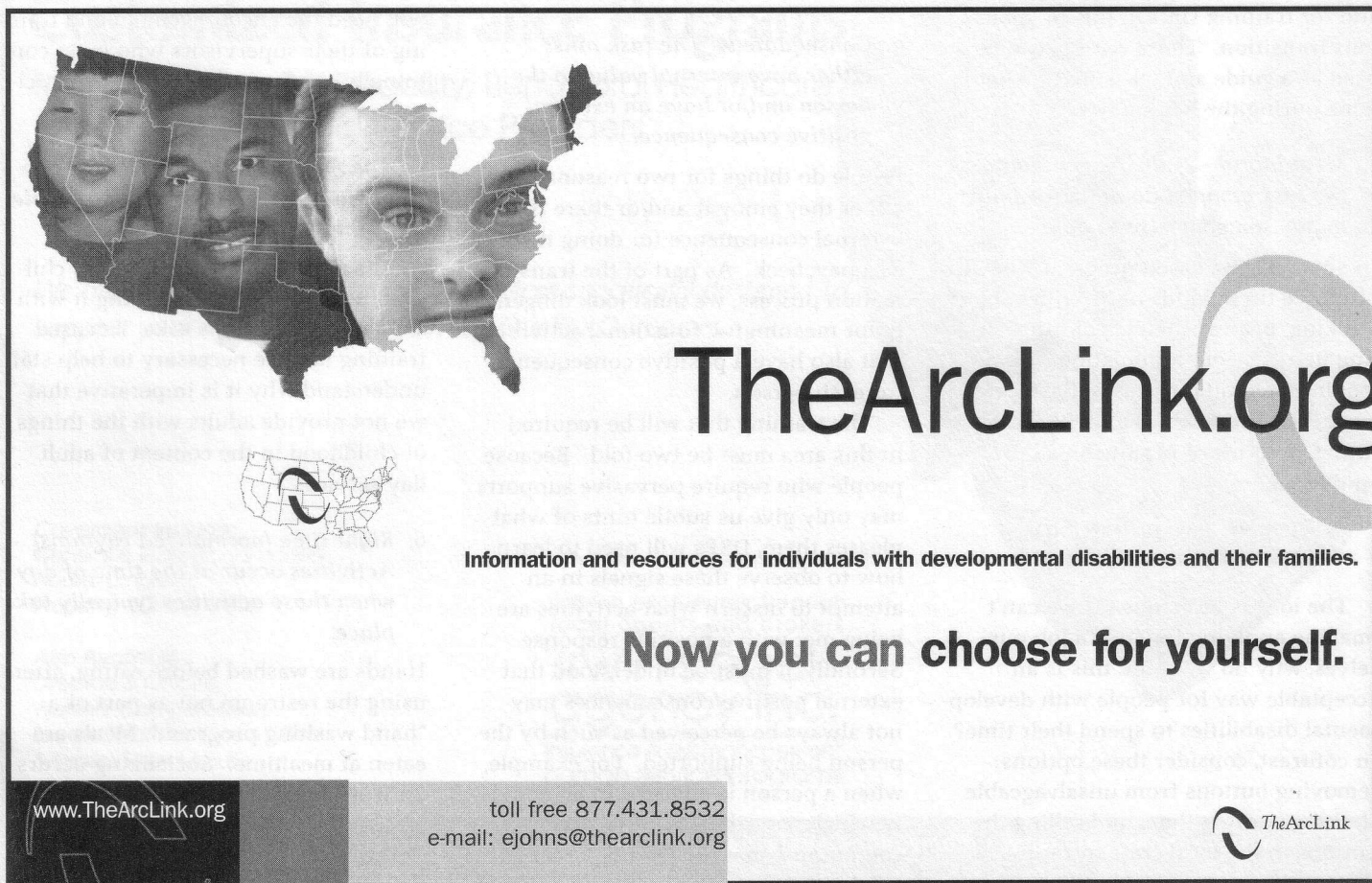
we shift the fundamental paradigm of adult day programs so that they help people towards meaningful lives? First and foremost, through our training programs we must reassure staff that what they have been doing all this time was not wrong. This approach was grounded in a philosophy that, in its time, provided people opportunities to have a level of engagement that allowed them to have some improvement in the quality of their lives.

If we begin with the widely held and reasonable assumption that what people with developmental disabilities want out of life is a real life, we must then ask ourselves, "What does real life look like for adults? What do adults do during the hours that adults with developmental disabilities are in day programs?" The answer is obvious and

leads us to this conclusion: what we must offer in place of day programs is **work**.

A growing number of organizations across the country are embarking on a journey of changing how adults are supported in day programs. Agencies are concluding that the only viable option out there is in fact work. In addition to being what most adults do, work has value that extends far and wide. Work is the great equalizer. Work builds self-esteem and confidence; work changes perceptions of the community at large about people with disabilities; work opens the doors to real relationships; work helps people gain valuable skills that they can use many places; work helps the adults we support fully enter the adult world

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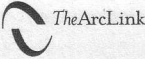


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as participants, not just observers; it allows people to become producers, not only consumers. Work is a critical piece of having a life.

Having said that, we must discuss and assess what work is. Work is not necessarily paid employment. In an ideal world with all resources, regulatory flexibility and creativity available to us, any person regardless of disability should be able to get paid to work. But in the real world of limited resources we must be willing to take what we can get closest to what we want.

**Work is the expenditure of meaningful effort.** Our problem now becomes operationally defining what Meaningful effort is. Those in our field who have been uncomfortable with the kinds of activities offered to people with disabilities have pressed for "meaningful activities." Defining what comprises a "meaningful activity" sometimes alludes us. The following are eight criteria that serve as the foundation for defining "meaningful activity" and for training staff in this momentous transition. These criteria can be used as a guide and measure of what is done during the work day.

1. *Meaningful – If the person doing the task stopped doing it, we'd have to pay someone else to do it.*

In a typical site-based program we will often see these kinds of activities: block stacking, bead stringing, coloring, sitting in a "sensory stimulation" room, making pretend purchases, flash card work – and so forth. Think of these things in terms of placing an ad for employment:

*Wanted: Two professional block stackers*

The idea is ludicrous. If we can't imagine applying for such a job ourselves, why do we think this is an acceptable way for people with developmental disabilities to spend their time? In contrast, consider these options: removing buttons from unsalvageable clothing, sorting them and selling the buttons to the local craft store; free form water color painting that's framed

and donated to a nursing home to decorate their walls; holiday centerpieces made to sell at an art fair; growing vegetables in a community garden and giving them to a local homeless shelter. The possibilities are endless. Training provided must help Direct Support Professionals (DSPs) tap into their creativity and resourcefulness and apply those qualities in their work.

2. *Functional – A person acquires a useful skill or ability as an outcome of doing the task.*

Eight people participating in the same activity may have eight different functional outcomes. For one it's attention to task, for the next it's improving his pincer grasp, for the third it's arm extension, for the fourth it's participating in a cooperative effort – and so on. As agencies transition forward, DSPs will need the assistance of clinical consultants to assess and determine what these functional outcomes should be for each person. Most training, in fact, will need to be guided by these clinical resources serving as trainers.

3. *Consequated – The task must either have internal value to the person and/or have an external positive consequence.*

People do things for two reasons; either they enjoy it and/or there is an external consequence for doing it such as a paycheck. As part of the transformation process, we must look diligently for meaningful, functional activities that also have a positive consequence for each person.

The training that will be required in this area must be two-fold. Because people who require pervasive supports may only give us subtle hints of what pleases them, DSPs will need to learn how to observe these signals in an attempt to discern what activities are being met with a positive response. Secondly, it must be understood that external positive consequences may not always be perceived as such by the person being supported. For example, when a person is engaged in an activity which contributes to the larger community, that person may not realize that this creates for them a positive

consequence of being perceived more favorably by others. Even if they do not recognize that a positive perception may alter their quality of life for the better, DSPs must understand and support such outcomes as they provide activity selections.

4. *Beginning to End – The person participates at some level in every step of the process.*

When professionals in this field see themselves as support people and stop seeing themselves as caregivers, this will not be difficult. People must be supported to engage in whole tasks; with encouragement to participate to the extent they are willing and able to do so. No longer do others do it for them. Someone wants a cup of coffee? Support them in choosing the beans, grinding the coffee, measuring the water and grounds, pouring it into a French press, pouring it out, enjoying it, then cleaning up. It will take longer, it won't be efficient and it will be a lot messier; facts that may be a source of consternation to DSPs. They will need the encouragement and training of their supervisors who must continually reinforce the idea that participation, not efficiency is the goal.

5. *Age Appropriate – The things people use are the things other people of the same age use.*

Adults should not use the things children use unless they are using it with a child for the child's sake. Focused training may be necessary to help staff understand why it is imperative that we not provide adults with the things of childhood in the context of adult day services.

6. *Right time (normalized rhythms) – Activities occur at the time of day when those activities typically take place.*

Hands are washed before eating, after using the restroom not as part of a "hand washing program." Meals are eaten at mealtime. Socializing occurs on work breaks. Day services will not be used to do things that should occur in the morning, evening or weekends. Bowling, movies, trips to the beach and

shopping are great activities but not during the week day. These are the purview of other types of services and supports.

7. *Right place (appropriate environment) – Activities occur in the place where those activities typically take place.*

Grooming occurs privately in a bathroom. Real purchases are made at stores. Meals are eaten at a table. Activities will be done only in appropriate and typical settings. Thus, for example, paying for one's meal at a fast food restaurant are not taught using fake money in a classroom. Both concepts of right time and right place only require that those providing the supports look to their own lives and those of most people around them to determine what is considered right times and places for activities. Thus, training must focus on identifying typical scenarios for tasks to occur, not to

create such scenarios artificially.

8. *Equal participation – The distinction between people supported and those providing the support must be minimized.*

As much as possible, people should not see the difference between these two groups. The way they look and act and their participation in activities should look more alike than different. One of the implications of this approach is a significant need to address the sometimes poor dress and hygiene of many of the people we support. We also must tackle the issue of inappropriate behavior people may engage in and that may be seen by others as either cute or obnoxious. (This is aside from behavior that is directly related to one's disability, such as the involuntary tics associated with Tourette Syndrome). At all costs the people we support must look good in the eyes of others. The flip side is that DSPs must not wear hospital scrubs, smocks or

other marks of being in a different or care giving role. Agencies pursuing this transformation of adult day services will hold high standards for how people present themselves, both the people supported and those doing the supporting. This is not particularly a training focus but requires those doing the support to pay attention to their self-presentation and that of the people they support.

Work must become the driver of any significant transformation of adult day services. As stated earlier, work provides the opportunity to "open doors" to real relationships. This important secondary function for day services (typically a primary focus of other supports such as residential services) is to support people in having valued relationships. Any one of us, whether we have one or two valued relationships or a whole host of them, would agree that they are distinctly important to

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our quality of life. We would be hard pressed to say that our families alone or people we pay for services are enough for us, and yet that is often all that the people we support have. Valued relationships cannot be mandated or guaranteed, but everything must be done to foster the potential for acquaintances and perhaps even friendships to grow. Through the use of neighborhood connections, common volunteer interest groups, going to the same places frequently, making introductions and supporting people to be the ones interacting with others on a regular basis, we can help people find opportunities for relationships to develop.

The training that will be required to accomplish this must focus on teaching DSPs how to forge and make the most of community connections as well as utilizing that most basic of skills – mak-

ing introductions. It will not do for DSPs to be the only ones interacting with the broader community. They must learn to see themselves as stage hands to the actors in the play of life, providing Individuals with the tools needed to strike up their own acquaintances.

It may be asked if this focus on having people work and supporting them to develop relationships will be effective. Can we actually help people get a life? Absolutely we can and it is our obligation, the reason we have our jobs. Perhaps the thorniest challenge that lies before any of us seeking to redefine adult day services is helping people break old habits, particularly those connected with care giving, and forge new ones. Training alone will not accomplish this. A radical culture shift, one that is defined by Good Enough for Me will help to move us forward. ■

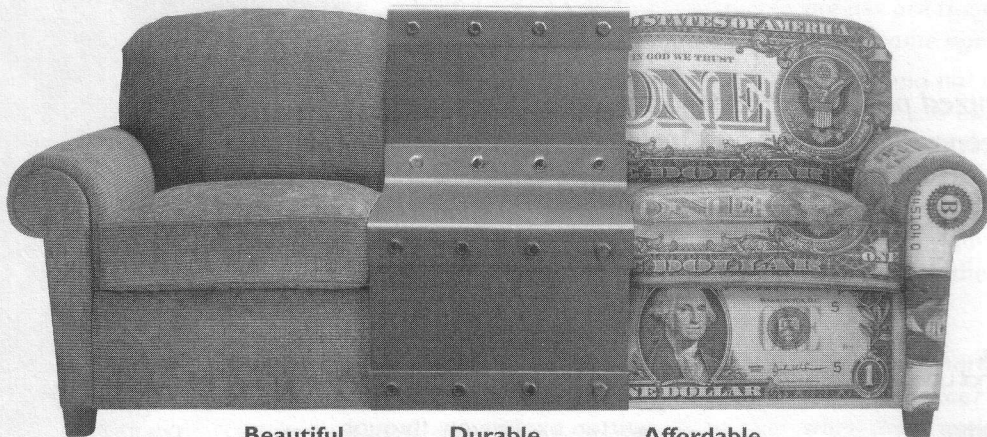
**AUTHOR LINK** Julie Eby-McKenzie is Director, Quality and Staff Development for Easter Seals Southern California. Working with consultant, Dr. Tom Pomeranz, Julie has embarked on a journey to change dramatically Easter Seals traditional Adult Day Programs to meaningful work that is respected by all. For further information regarding this transition or other information concerning Easter Seals of Southern California, contact Julie at [julie.ebymckenzie@essc.org](mailto:julie.ebymckenzie@essc.org).

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