

# WHAT'S UP WITH SERVICES?

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What's up with services in the year 2001? Nothing really new. A look back over the last twenty-three years at special education services and adult services for people with developmental disabilities reveals that not much has changed.

Twenty-three years ago, when the IDEA was in its infancy, special education was delivered to groups of children with labels in congregate settings. Schools attempted to satisfy the IDEA's least restrictive environment provisions by having some of these children attend a regular physical education class, or spend lunch as a group in the lunchroom with typical children. Regular education teachers of the school's general academic curriculum were reluctant to provide services in their classrooms, and were without appropriate training to provide such services.

Furthermore, schools developed programs for children based on categories of their disabilities. An individualized education program (the "IEP") was developed at a meeting that fit the characteristics of the services that would be provided in the already developed program. The IEP, a document that was supposed to contain the special curriculum and services to meet the unique needs of a child with disabilities, was developed in a generalized fashion to fit the program and to be delivered to groups of students. These IEP's contained general goals, general objectives, and no baseline information from which to measure the child's progress.

Twenty-three years later, special education services are still being delivered to groups of children in congregate settings, with different labels, i.e., the SLIC Program Student, The Challenge Program Student, etc. Inclusion into regular education classrooms is the exception, not the rule. In most cases, when inclusion does take place, it is in a regular education classroom with an apathetic and non-trained regular education teacher, who spends little, if any, time with the included student with the excuse that the teacher must not detract from the teaching of the typical students in the regular classroom. "They have a right to an education too."

While the school forms for the IEP's have changed, content has not. Even today, goals and objectives are general and vague, and geared to the congregate program setting to meet the students disability classification. As a result of the general and vague goals and objectives, and consistent failure to develop baseline data from which to measure, a student's progress is almost impossible to objectively measure. The concept that an IEP is supposed to be an individualized curriculum to meet the unique needs of a single student with disabilities continues to be lost.

Adult services have not fared any better. Years ago services to adults with developmental disabilities were delivered at large institutions. Community involvement or employment was not a consideration. As time passed, there has been a downsizing of large institutions and the creation of work opportunities. These efforts took the form of group homes and congregate sheltered workshops.

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Not only are large institutions still around to a limited extent, but today adult residential services for persons with developmental disabilities are provided in community group homes & congregate apartment settings that are nothing more than mini-institutions. Sheltered workshops still exist or have given way to “Day Programs” or “Community Participation Programs” that are little more than moving persons with developmental disabilities out of the congregate sheltered workshop setting to a congregate community setting, where groups of adults are at best shipped by van from one community activity to another throughout the day. While the adult service system aspires to champion competitive employment for persons with developmental disabilities, these employment opportunities are significantly limited.

In addition to these shortcomings, the quality of direct supports to persons with developmental disabilities is regressing. Those who provide direct supports to adults in residential and employment or community activities are motivated to be caregivers as opposed to being a support to individuals to become more independent, and have more choice and control in their lives. With few exceptions, there is an obvious inability to value individuals with developmental disabilities as “people.” In the adult service system, self-determination, independence, choice and control are intellectual concepts rarely put into practice.

Just as disturbing is the failure of the adult service system to provide persons with developmental disabilities a quality “individualized plan” (the “IP”). Too many IP’s are poorly written and exclude specific services that will drive outcomes of self-determination, independence, choice, competitive employment and community involvement. When an IP is properly developed to include these important elements, it too often is put in a file and not implemented in accordance with its contents.

Twenty plus years is too long a time for so little improvement. Real progress in improving the quality of life for persons with developmental disabilities is only going to happen by pushing the envelope. Grassroot efforts by all families, friends and advocates of persons with developmental disabilities must re-emerge. A few hired professional advocates supported by the same core group of volunteers can not accomplish the cause by themselves.

To push the envelope, the systems that are failing must be challenged. Understand that the IEP and the IP are equivalent to a contract that the system agency has a legal duty to properly develop and to fully implement. Parents, guardians and advocates must have, at a minimum, a working knowledge of what is required to be contained in an IEP and an IP, and the needs of the person who they support. An IEP or IP meeting should never be adjourned until everything required to be contained is contained in the IEP or IP, and all of the needs are addressed.

Once the IEP or IP is properly developed, its implementation must be monitored. Don’t wait for months to determine whether the system agency is carrying out the terms of the contract, because valuable time in the life of the person being supported will be lost. This part of the person’s life can never be recouped. When it is discovered that the implementation is not being carried out, don’t be afraid to use the grievance procedures in both the education and adult service systems to enforce their rights. That’s what the procedures are there for.

**Make progress happen. Get energized!**