THE "WHY QUESTION" IN INSTRUCTIONAL PROGRAMS FOR PEOPLE WHO ARE SEVERELY INTELLECTUALLY DISABLED¹

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INTRODUCTION

Special Education for the lowest intellectually functioning one percent of our population can never be viewed as an end, only a means. A means to a decent chance to function with proficiency, individuality and responsibility in small, warm and individually responsive family style homes; to perform meaningful jobs in the integrated world of work; to realize personal joy and fulfillment in the recreation/leisure environments and activities utilized by people who are not disabled; and to utilize an expanded array of rich and varied environments in the general community.

If we examine the effectiveness of educational and other instructional services offered to people with severe intellectual disabilities historically, it appears that integrated postschool life spaces have been arranged and realized for only a meager few. Most pass through adulthood experiencing only constricted, antihabilitative, devalued and unnecessarily costly segregated environments and activities (Buckley & Bellamy, 1986; Hasazi, Gordon, & Roe, 1985; Mithaug, Horiuchi, & Fanning, 1985; VanDeventer, et al., 1981; Wehman, Kregel, & Seyfarth, 1985; Wheeler et al., 1983).

There are many reasons why people are labelled severely intellectually disabled by practicing

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professionals². One of the most basic is that they acquire **substantially** fewer vocational, domestic, community and recreation/leisure skills than 99% of the rest of the population (Brown et al., 1983). If an individual is projected to acquire fewer skills than virtually everyone else, it is critical that the skills selected for instruction be the most important. The problem, of course, is the process used to determine whether a particular skill is important and valuable, as opposed to unnecessary and wasteful.

One process that can be used when selecting specific skills for instructional purposes is offered here; that is, the systematic use of the "Why Question." The "Why Question" requires professionals to clearly articulate the reasons why one particular skill is selected over all others, <u>before</u> instruction begins. Specifically, when a skill is being considered for instruction, a series of

The label "severely intellectually disabled" refers to approximately the lowest intellectually functioning 1% of a naturally distributed population. This 1% range includes people who also have been ascribed such labels as psychotic, autistic, moderately/severely/profoundly retarded, trainable level retarded, physically handicapped, multihandicapped, and deaf/blind. Certainly, a person can be ascribed one or more of the labels delineated immediately above and still not be referred to as severely intellectually disabled for purposes here, as he/she may not be currently functioning intellectually within the lowest 1% of the population. important questions must be answered in professionally
defensible ways. Some, but certainly not all, of these
questions are:

- Given a population of skills that might be taught, can those selected be deemed the most important both now and in the future?
- 2. Will the skills selected yield the best possible instructional gains for the resources invested?
- 3. If selected, will the skills be those most likely to enhance the individual's quality of life?
- Does the skill have potential for being useful to the community at. large?

Other strategies for selecting particular skills for instructional purposes are presented by Sailor and Guess (1983), Savage (1983) and Snell (1983).

WHY A SKILL SHOULD BE SELECTED

A dimension refers to a characteristic that can vary. Height, skin color, running speed and spelling ability are but a few examples. In this section, eleven dimensions and related phenomena will be delineated, defined and discussed in relation to the <u>A Priori</u> selection of a skill for instructional purposes. The reader is asked to realize:

- That the dimensions delineated are neither mutually exclusive nor exhaustive;
- That each dimension must be viewed in relation to all others;
- That synergistic relationships between dimensions should be assumed;
- That acceptable ideological positions on these dimensions must be realized <u>before</u> a skill is selected for instruction; and
- 5. That if extreme positions are taken in relation to one dimension, reasonable positions in relation to others are virtually impossible.

The dimensions to be considered in the selection of skills for instructional purposes are listed in Table 1. A discussion of each dimension follows.

Insert Table 1 About Here

INCREASING THE NUMBER OF ENVIRONMENTS

Increasing The Number of Environments refers to expanding the actual number of discrete places one enters and leaves each day, week and year. Almost all individuals with severe intellectual disabilities frequent fewer environments per unit of time than nondisabled people of the same chronological age or older (VanDeventer et al., 1981). One way to interpret this relative paucity of environments experienced is that such individuals have unnecessarily constricted life spaces. An important instructional objective must be to increase the number of environments in which a person functions until that number is in reasonable accordance with those frequented by people without disabilities. This objective is necessary if an individual is to have the most normalized life style possible.

Historically, the strategy of "Increasing the Number of Skills" has been used as a vehicle to increase the number of environments experienced. That is, an individual is confined to a few instructional settings per week. Attempts are then made to teach many skills. It is presumed that if many skills are taught, the number of environments to which a person is allowed access will then increase. Such , a strategy has not yielded meaningful instructional returns for invested resources (Buckley & Bellamy, 1986). For example, imagine two 21-year-old people who have just completed their public school careers. One has a repertoire of over 10,000 skills and the other has one of less than 200. The historic assumption has been that the individual with the larger repertoire will have access to more environments than the other. No longer can

this assumption be considered empirically tenable (Biklen, in press). If you are an adult who is severely intellectually disabled, chances are overwhelming that a special vehicle picks you up at your house in the morning, takes you to an activity center or a sheltered workshop and returns you to your house in the evening. There you will stay until the vehicle comes the next day. Your skill repertoire can be limited or remarkably varied, but it will not affect the number of environments you experience. Conversely, a few people with severe intellectual disabilities have relatively limited skill repertoires, but experience remarkably stimulating lives and frequent a variety arrays of enhancing environments (Brown et al., 1986).

An alternative strategy is offered here. The number of environments in which a person with severe intellectual disabilities actually functions is increased immediately so that differences in relation to nondisabled people of similar chronological age are minimized. Having increased the number of environments, all instructional services designed to engender meaningful skill repertoires or to otherwise enhance functioning in each environment are provided.

In summary, a critical question that must be asked in the skill selection process is: will acquisition of the skill enhance functioning in an increased number and range of environments? If the acquisition of a skill will not directly lead to or enhance functioning in an increased number and array of environments, it is viewed as less valuable or less important than others that will. Therefore, it is extremely important to identify environments that will enhance the life space of the individual and to teach the skills essential for success therein³ (Brown et al., 1984).

FUNCTIONALITY

Functionality refers to an action that will be performed by a nondisabled person, if it is not performe by an individual with severe intellectual disabilities.

<u>Sue</u> is being taught to put stamps on envelopes. Is this action functional? In this instance it is because she did not do so, her group home manager would have to the envelopes contain checks assigned to pay bills. Putting stamps on the envelopes would not be considered functional if another person was not required to perform the same task.

³In this context "life space" refers to factors and experiences that impinge upon a person 24 hours per day, days per week, 365 days per year. John is being taught to put pegs in a peg board and vacuum a rug in a simulated work environment. Are these actions functional in accordance with the definition offered? No, because if he did not put pegs in the peg board, they would not be so placed by a nondisabled person, and if he did not vacuum the rug, it would not be necessary for a nondisabled person to do so.

Instructional programs for people with severe intellectual disabilities should be committed to teaching an individually determined but developmentally defensible number of functional skills. Which, how many, how often, etc., can only be determined on an individual basis. An instructional program that does not attempt to teach the performance of functional skills is inherently unacceptable. In contrast, an instructional program that teaches only functional skills, while perhaps slightly better, is also unacceptable. While there may not be much to a quality of life if a person cannot perform functional skills, there is probably not much more to a quality of life if a person only performs functional skills. Watching a sunset, listening to music, fishing and strolling in a park, are but a few examples of skills that would be considered other than functional under the definition offered. The reader interested in a supplementary discussion of functionality is referred to Brown et al. (1984).

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CHRONOLOGICAL AGE APPROPRIATENESS

Chronological Age Appropriateness refers to skills, attitudes, instructional materials, environments and activities that are associated in affirmative, culturally sanctioned and respected ways with particular age groups. Jim is severely intellectually disabled and 23 years old. At his last birthday party, his father gave him records by Bruce Springsteen, Madonna and Billy Ocean. <u>Paul</u> is also severely intellectually disabled and 23 years of age. His uncle gave him three records for his birthday. One was the story of Peter and the Wolf and the others contained nursery rhymes.

In accordance with the definition offered, Jim received chronologically age appropriate gifts and Paul did not. That is, chances are great the 23-year-olds who are nondisabled would receive the music of Springsteen, Madonna and Ocean, not the music typically ascribed to nondisabled children under the age of 5.

The instructional assumption here is that all education, communication and other service needs can be met in chronologically age appropriate ways. Specifically, phenomena of a chronologically age appropriate nature can and should be experienced, preferred and enjoyed by someone who is severely intellectually disabled. Denying access to such phenomena is unacceptable in that a normalized and dignified lifestyle will forever be unattainable.

PRACTICE

Practice refers to the performance of a skill under noninstructional conditions once it has been acquired. <u>Kevin</u> was taught to make toast using a toaster in his supported apartment by his nondisabled housemate. Once this skill was taught under instructional conditions, arrangements were made for him to make his toast every morning unsupervised.

Two of the criteria for labeling people severely intellectually disabled are that they manifest more long and short term memory difficulties than 99% of the general population. Further, once they forget that which has been learned, they are likely to take longer and to need more instructional trials in order to relearn or recoup than all nondisabled peers (Brown et al., 1983). In general, if we know an individual is highly likely to forget and that recoupment will require almost as many resources as original learning, we should not select a skill for instruction without a prior commitment for practice opportunities under noninstructional conditions. However, there are exceptions.

<u>Dave</u>, age 20, is a nonambulatory severely intellectually disabled individual who lives on a ward of a local institution for people who are retarded. He attends a chronologically age appropriate regular public school. His teacher has decided to teach him to use a picture

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communication booklet to assist him in ordering food in a public restaurant, planning meals, and performing household **chores.** Unfortunately, opportunities for the practice of these skills in the noninstructional environments (the institution) in which he currently functions (the institution) are nonexistent. Nevertheless, the skills were selected because the instructor judged that acquisition would enhance probabilities of him being placed in a normalized community living environment.

In summary, it is extremely difficult to justify the selection of a skill for instructional purposes without prior commitments from noninstructional personnel that opportunities for practice will be arranged consistently. <u>A Priori</u> practice commitments from noninstructional personnel also require the support and systematic involvement of parents, guardians, brothers, sisters and significant others in the instructional process.

REQUIRED AS AN ADULT

Required as an Adult refers to whether or not a skill being considered for instruction is required, needed, respected or allowed expression in adulthood. <u>Judy</u> is 24years-old and severely intellectually disabled. She is being taught to clap her hands, touch her nose, shake her head and wiggle her toes when she is happy and she realizes it. Carol is 24-years-old and severely intellectually disabled. She is being taught to alert group home parents when her television needs adjustment, to express preferences for music and to request bait from fishing companions.

When The Required As An Adult Factor is considered, the more appropriate skills would be those being taught Carol. That is, even though acquisition may take longer, the skills she is being taught will be important and respected throughout her adult life. Generally, if a skill is appropriate for performance in adulthood, it is considered more acceptable than others that are not.

INDIVIDUAL PREFERENCE

Individual Preference refers to arranging for and allowing a degree of choice in the selection of skills that will be learned. Allowing an individual to choose all the skills that will be addressed instructionally is inherently unacceptable because only those that are enjoyable might be selected and those that might be critical for maximal productivity in important environments and activities might **be neglected.** Conversely, not allowing participation in the choice making process in relation to at least some of the skills selected for instruction is equally unacceptable (Shevin, 1983).

There are several important reasons why individuals with severe intellectual disabilities should be allowed to influence skill selection through expressions of personal
preferences:

- Most nondisabled individuals are responsible for deciding many of the skills they will learn;
- Participation in the skill selection process increases the likelihood of extended effort in the associated instructional activities;
- All training programs should provide practice in decision making; and
- A. Participation in decisions that affect an individual is a basic right that humans should extend to other humans.

If people with severe intellectual disabilities are to have the most fulfilling and normalized life styles possible, they must have opportunities for choice making. Only when these opportunities are given can maximum societal acceptance and self worth be realized.

PARENT/GUARDIAN PREFERENCE

Parent/Guardian Preference refers to securing the extremely important contributions parents and guardians can make to instructional programs. In the past when parents/ guardians banded together to establish and operate much needed day services for their children because public school personnel would not, many actually determined the nature of the entire experience. Teachers and other direct service personnel were allowed limited, if any, professional input. Conversely, there have been professionals who have systematically and effectively excluded parents/guardians from even minimal involvement in the design and implementation of instructional services. Educators and adult service providers now realize that parent/guardian involvement in the instructional process is critical. They also realize that a constructive balance between parent and professional decision making is appropriate and educationally sound (Shevin, 1983).

All reasonable attempts should be made to ensure the informed and consistent input of parents/guardians into the design and implementation of instructional programs. The delicate professional issues seem that of balance and proportion. Specifically, issues concerning how much decision making authority and what decisions should be ascribed to parents; how much decision making authority and what decisions should be ascribed to professionals; and what decisions should be rotated, compromised or made jointly must be determined individually (Sweet et al., 1984; Turnbull, Strickland, & Brantley, 1982).

PHYSICAL ENHANCEMENT

Physical Enhancement refers to selecting a particular skill for instruction because its performance will enhance

the physical well being of the individual. Conversely, it refers to avoiding the instruction of skills that may have negative and, in many instances, neutral effects on physical well being. Almost all people with severe intellectual disabilities function with impaired bodies and/or are in substantially less than acceptable physical condition. These impairments often have long-term deleterious effects on employment, recreation/leisure and wide variety of other life space opportunities. Thus, it is extremely important that many skills likely to enhance physical well being be selected for inclusion in instructional programs. Assume an instructor was deciding whether to teach a client to indicate that he wanted to bake a cake or to go swimming. With consideration given many other dimensions and related factors, it was decided to teach the swimming related skills because they offered better chances of realizing improvements in physical well being.

SOCIAL CONTACT ENHANCEMENT

Social Contact Enhancement refers to selecting a skill because it is likely to increase the probability of appropriate interactions with nondisabled people in integrated environments. <u>Rex</u>, who is severely intellectually and physically disabled, was taught to present pictures of food items to clerks at fast food

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restaurants. This skill allows him to establish contact, to exchange information and to enjoy pleasant social interactions with anonymous nondisabled people.

It is extremely important that a substantial proportion of all instruction offered individuals with severe intellectual disabilities be oriented toward teaching skills that facilitate social interactions with nondisabled people in integrated environments.

ACQUISITION PROBABILITY

Acquisition Probability refers to the relative likelihood that a skill will be acquired, if reasonable resources are devoted to its instruction. Obviously, skills that have from zero to 100% probability of acquisition can be selected. However, unless other dimensions are considered, acquisition may be meaningless. For example, 25-year-old <u>Sara</u> can easily learn to assemble a three piece Donald Duck puzzle. Unfortunately, the skills required are not functional, chronologically age appropriate, status enhancing, etc.

Selecting a skill for instruction just because it is highly likely to be acquired is unacceptable. Selecting a skill that is highly unlikely to be acquired, however potentially valuable, is equally unacceptable. The decision of choice is to select a skill that is valuable and that can be acquired given reasonable instructional resources. Jim will require intensive instruction over a **relatively** long period of time to operate an electric **wheelchair** safely and efficiently. Nevertheless, this skill has been selected because: it will increase the number of environments to which he will have access; it will increase opportunities for social interactions with people who are not disabled; and it will enhance his status.

STATUS ENHANCEMENT

Status Enhancement refers to the relative effects performance of a skill is likely to have on the positive social status of a person who is disabled. Given two or more skills, the one more likely to enhance social status should be chosen.

<u>Tim</u> is severely intellectually disabled and has no arms or legs. At his work site he was taught to stamp envelopes using a prosthetic arm. After doing quite well at this, additional work tasks were considered. From a list of possible options, Tim, the employer and his job coach selected a typing task because it would enhance his status in the work environment.

WHY A SKILL SHOULD NOT BE SELECTED

In the previous section, attempts were made to articulate a list of factors, concepts and values that can be used to select valuable skills for instruction. The assumptions are that there is a large number of skills that can be taught and that there should be many good reasons for selecting a particular one. Conversely, there are many skills that should not be selected because there are few good reasons to justify their instruction.

Several unacceptable justifications for the selection of skills for instructional purposes will be addressed. The primary reasons for referring to these justifications as unacceptable are:

- That they rarely represent credible positions on the dimensions delineated;
- That they rarely lead to the instruction of real skills in the real world;
- That meaningful individualization is extremely unlikely; and
- That the creativity and ingenuity so important to adequate instruction are minimized.

THE KIT MAKERS SAY TO DO IT

One of the authors visited an instructional session offered by a speech and language pathologist. She was sitting behind a semicircular table and four individuals with severe intellectual disabilities were distributed around the outside rim and facing her. She said, "Make this sound," and she made an "S" sound. Unfortunately, **these** individuals were unable to respond appropriately. When asked **why** she was attempting to teach the skills necessary to imitate the "S" sound she replied, "It says to do so on page 12 of the QRAB-PLOCK-RXTZ-DIPPYDO KIT."

Many professionals attempting to develop the skill repertoires of individuals with severe intellectual disabilities obtain their instructional objectives and materials from commercially available "kits." The contents of these kits are usually based upon one or more theories of normal human development, hypotheses related to prerequisites of mature intellectual functioning and popular interpretations of prevailing or emerging language development systems. Professionals using such programs often assume that the producers have sufficient justification for the instructional sequences therein.

Prepackaged sequences, clusters of core skills, standardized instructional activities and materials and other such phenomena are generally inapplicable and substantially inappropriate for use in instructional programs for individuals with severe intellectual disabilities. Deciding what a person should learn without having spent considerable time with him/her, without basic knowledge of current assets and liabilities and without comprehensive information about the current and most likely subsequent environments and activities in which he/she will function is a less than acceptable instructional practice. Certainly, limited use of some commercially prepackaged information may be appropriate. However, it must be scrutinized carefully and rejected whenever it is in conflict with acceptable positions on at least the eleven dimensions delineated.

I WAS TRAINED TO DO IT

Several years ago one of the authors visited a classroom operated by a teacher with a Master's Degree in Special Education. She was instructing a 19-year-old young man with severe intellectual and physical disabilities, including limited use and control of his arms and hands, to pick up a plastic egg and place it in a plastic refrigerator door container. When asked why this skill was selected for instruction she replied, "I was trained to do it."

At face value this justification seems neutral, but is usually negative. That is, many Special Education teachers, administrators, psychologists, physical therapists, speech and language pathologists, and others have been trained to teach skills that would now be considered unacceptable in relation to some or all of the eleven affirmative dimensions and related factors delineated earlier in this chapter. Indeed, considering how rapidly Special Education and other services for people with severe intellectual disabilities are evolving, training offered only a few short years ago in many instances is hopelessly outdated and in some cases even harmful. In short, "I was trained to do it," is not a sufficient justification for skill selection. What someone was trained to do must be referenced against at least the eleven dimensions presented. If it is not, risks of offering inadequate instruction are too high.

THAT IS WHERE SHE IS DEVELOPMENTALLY

<u>Sally</u> is 20 years old, still in school and severely intellectually disabled. At her group home she is being taught to visually track a ball as it rolls across a table. When her instructors were asked why she was being taught this skill, they replied that she was given tests that compared her performance to that of normally developing two-year-old children and the level at which she scored dictated that she should be taught skills such as this.

Certainly all people should be given opportunities to progress through prevailing views of normal human development stages and phases. The problem for individuals with severe intellectual disabilities, of course, is that they require many more instructional trials and longer periods of time to acquire almost any skill. Thus, they begin life substantially behind normally developing children and, through the long term use of normal human development strategies, their differences actually increase over time.

Perhaps normal human development hypotheses can be combined with other dimensions and used to justify skill selection when students with severe intellectual disabilities are very young. However, with increases in chronological age, such theories must be viewed with cumulative professional skepticism and replaced with more appropriate curriculum development strategies. The second major problem for those who answer the "Why Question" with normal human development hypotheses is that normal human development based curricular strategies rarely, if ever, result in the skills, attitudes and values necessary for reasonable functioning in integrated work, play and living environments and activities at age 21.

SUMMARY AND CONCLUSIONS

A basic goal of instructional programs for individuals with severe intellectual disabilities is preparation for meaningful functioning in integrated work, play, domestic and general community environments. Being able to generate professionally responsible answers to the "Why Question" is an integral part of providing the instructional experiences so important to a decent quality of life.

When a professional is asked why he or she has decided that a person with severe intellectual disabilities should be taught a particular skill, he or she should be able to respond with a series of specific, enhancing and affirmative reasons. For example, the reasons Joe Smith will be taught to perform Skill A are that:

- It will increase the number of environments in which Joe can operate;
- If he does not do it, a nondisabled person will have to;
- 3. It is chronologically age appropriate;
- It will enhance his status in the eyes of many nondisabled people;
- His parents clearly prefer that he learn it;
- 6. He will enjoy being able to perform it;
- He should be able to acquire this skill in a reasonable period of time;

- Opportunities for post acquisition practice have been arranged;
- It will enhance his physical well being;
- 10. It is required of him in adulthood; and
- 11. It will increase his chances for positive social interactions, particularly with nondisabled people.

The basic reason for utilizing the eleven dimensions is that they are considered inherently more acceptable than others that are often used. "I picked this skill because it says to teach it in lesson seven of the PREPAC PLASTIC FRUIT KIT," or "because normal infants with the same mental, social, sensorimotor, language and cognitive ages learn it" are but a few examples.

Finally, the reader should be cautioned that while the "Why Question" is the focus here, other important phenomena must be factored into the instructional equation and treated with at least as much intellectual scrutiny. <u>Where</u> instruction should be provided, what are the natural <u>performance criteria</u>, <u>who</u> can best provide the instruction, what are the most realistic and appropriate <u>instructional</u> <u>materials</u>, <u>how</u> is the individual going to be taught the skill selected and what are the <u>measurement strategies</u> that will be used to empirically verify progress or lack thereof are but a few.

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TABLE 1

Dimensions Considered When Selecting Skills for Instructional Purposes

Dimensions

Increasing the Number of Environments Functionality Chronological Age Appropriateness Practice Required as an Adult Individual Preference Parent/Guardian Preference Physical Enhancement Social Contact Enhancement Acquisition Probability Status Enhancement

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