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# The Promise of Adulthood


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## The Promise of Adulthood

*Philip M. Ferguson*

*Dianne L. Ferguson*

In his last year of high school, Ian Ferguson learned to fly. This was quite an accomplishment for someone labeled severely mentally retarded and physically disabled. As Ian's parents, we marveled at his achievement and worried about the law of gravity. Let us explain.

*As part of Ian's final year as a student – nearly 20 years ago now – he enrolled in “Beginning Drama.” Following his carefully designed transition plan, Ian spent most of the rest of his day out in the community: working at various job sites, shopping at various stores, eating at various restaurants. But he began each day in drama class with a roomful of other would-be thespians. The logic behind Ian's participation in the class at the time was that it might lead somehow to his adult participation in some aspect or other of Community Theater. You see, while Ian's vision is poor, his hearing is great. In fact, he finds odd or unexpected sounds (human or otherwise) to be endlessly amusing. During high school, one of our more insightful friends bought Ian a set of sound effects tapes of the type used by theater groups (e.g., “Sound A-24, woman screaming, 27 seconds” [screaming ensues]; Sound A-25, man sneezing, 15 seconds ...) as called for by various productions. Surely, we reasoned, Ian could learn to control his laughter long enough to help in such offstage activities as the making of sound effects. Furthermore, the drama teacher at Ian's high school just happened to be quite active in Community Theater in our town. Our objective, then, was really to see if we could figure out how Ian might participate in community theater productions as an adult leisure activity, possibly “networking” with the drama teacher to gain an entrée into that group.*

*To our pleasure, Ian benefited in many more unexpected ways from his introduction to the dramatic arts: memorization, articulation, expressiveness, and social interaction. He also learned to “fly.” A major part of the first few weeks of class involved Ian's participation in “trust” exercises. Some students fell off ladders, trusting*

*their classmates to catch them. Others dived off a runway with the same belief that their friends would break their fall. The exercise that Joe Zeller, the teacher, picked to challenge Ian was called “flying.” Seven or eight of Ian’s classmates were to take him out of his wheelchair and raise him up and down in the air, tossing him just a little above their heads.*

*Now, the first time they tried this everyone was very tense. Both Mr. Zeller and Leah Howard (Ian’s support teacher) were nervous; it was an adventure for them as well. The students released Ian’s feet from their heel straps, unbuckled his seatbelt, and, leaning over en masse, lifted him out of his chair. Joe and Leah positioned themselves at the most crucial locations on either side of Ian and slowly—together with the students—began to raise Ian’s supine body with their hands. Now it was Ian’s turn to be nervous. Ian’s spasticity makes it impossible for him to break a fall by throwing out his arms. Several painful crashes have left him with a strong fear of falling at the first sensation of being off balance or awkwardly positioned. Like many folks who experience his kind of physical disability, Ian has a hard time trusting strangers to move the body that he has so little control over. As the students lifted him, he clutched nervously at the only wrist within reach of the one hand he can use, trying to find something to hold on to. His voice anxiously wavered “Leah, Leah,” seeking reassurance that this was, in fact, a wise course of action. It was pretty scary for Ian and pretty risky for everyone else. But the exercise went well. Months later, when the drama class repeated some of the same trust exercises, Ian greeted the suggestion that he “fly” with an eager response of “Out of chair! Out of chair!” That is how Ian learned to “fly” in his last year of school. The secret was building on his eagerness to be a true member of the class to learn to control the fear of falling. It is a lesson that has served us all well in the ensuing years.*

We tell this story about “flying” in drama class because it also captures the simultaneous sensations of excitement and anxiety that we experienced as Ian finished high school and launched into adulthood. We were fairly certain that Ian had some mixed feelings as his old routines and familiar settings vanished and new activities and settings took their place. The people in Ian’s social network of formal and informal supports and friendship also recognized the responsibility that enough hands be there to “catch” Ian if he started to fall. As Ian left the relative stability of public school, grounded as it is in legal mandates and cultural familiarity, we worried about the thin air of adulthood where formal support systems seemed to promise little and accomplish even less.

Ian has just turned 40. He lives in his own home, works at a job that he has enjoyed for nearly 20 years, and ac-

tively participates in a full schedule of household tasks, social engagements, parties, chores, weekends away, and occasional vacations. He did participate as a member of the cast in a local production of *Oklahoma!* directed by his high school drama teacher as we had hoped. He is supported in his adult life by a network of paid and unpaid people, a personal support agent who also provides direct support, and our ongoing involvement to ensure that his life is more okay than not okay from his point of view most of the time.

Our journey through these years has been difficult, often confusing and frustrating, but also filled with many exciting achievements. We have all learned a good deal about how one young man can negotiate an adult life and the kinds of supports that requires. We have also met many others who are making the same journey with a similar mix of frustration and achievement. We, and they, continue to struggle with a variety of thorny issues. How do we make sure that Ian's life is really *his* life and not one that merely reflects the regulations, individual support plan procedures, agency practices, and other formal service trappings? How do we ensure that Ian's life is not a program? How do we assure ourselves that Ian is somehow contributing to all the choices that get made about what constitutes a good adult life for him? We have created new options for Ian and others as we have struggled to answer these questions. We have also increased our understanding of what it means for someone who has a variety of severe disabilities to be adult.

## **EXPLORING THE PROMISE OF ADULTHOOD**

In this chapter, we want to explore this status of adulthood and how it applies to people with severe disabilities. Our point is not that people with severe disabilities who are over the age of 18 or 21 are somehow not adults; of course they are adults. The problem is that our field has not spent enough time thinking through exactly what that means in our culture and era. Adulthood is more than simply a chronological marker that indicates someone is above a certain age. As important as having a meaningful job is or living as independently as possible, adulthood seems to involve more than this. As one social commentator has framed this distinction, "In many ways, children may always be children and adults may always be adults, but conceptions of 'childhood' and 'adulthood' are infinitely variable" (Meyrowitz, 1984, p. 25). If it is our responsibility as teachers and parents of students with severe disabilities to "launch" them as successfully as possible into adulthood, then it should be worthwhile to reflect on what promises such a role should hold. What is the promise of adulthood for people with severe disabilities?

We are not so bold as to think we can fully answer that question in this chapter. Our effort here will be to begin a discussion of the issue that we think needs to continue within the field of severe disabilities in general. We will organize our effort into three main sections: (a) understanding adulthood, (b) denying adulthood, and (c) achieving adulthood. Finally, throughout our discussion, our perspective will be unavoidably personal as well as professional. We will not pretend to be some anonymous and “objective” scholars writing dispassionately about the abstraction of adulthood for people with severe disabilities. Our son, Ian, is one of those people, and he is far from an abstraction to us. We will mention him throughout this chapter to illustrate some points we make and to explain our perspective better. We will also share about another young man that we have known for over 20 years whose journey as an adult is both similar and different than Ian’s. However, we will also not write only as Ian’s parents or Douglas’ friend. We will draw on our own research and that of other professionals and scholars in disability studies to bolster our discussion as well. Such a mixture of the personal and professional perspective does not only affect us as the writers; it should also affect you as a reader. You should read and respond to this chapter as a discussion of the concept of adulthood in general but also as it fits (or does not fit) with your own personal experiences of people with severe disabilities.

*We first met Douglas and his family a little more than 20 years ago when we started teaching each summer in Atlantic Canada at a local university. For three weeks each July our lives alternate between teaching classes to teachers, exploring the Maritime Provinces and spending time with people that have become friends. Douglas’ mother was a professor at the university and invited us not only to teach, but to dinner and through her we met – over the years – not just Douglas but the whole family. After the first year or two, we have appreciated as one of the best parts of our visit Douglas’ greeting each time. He seems to be most excited to see Phil – especially now that they wear similar small beards – but we take his enthusiastic greeting as a welcome to us both. Douglas expresses himself clearly, but rarely with words that anyone but his mother or father understand. He is, however, a presence in his home, his town, and our memories of each of our summers in this part of Canada. We will share some of our experiences with him and some aspects of his life throughout this chapter.*

## UNDERSTANDING ADULTHOOD

The concept of adulthood is a fluid one that changes from era to era and from culture to culture (Ingstad & Whyte, 1995). For most European cultures, adulthood has a strong individualistic (or “egocentric” in anthropological terms) emphasis on personal independence and achievement. For many non-Western cultures, however, adulthood has a stronger emphasis on social affiliations and connectedness (or “sociocentric”). Even within our own American culture, the interpretation of adulthood has always undergone gradual historical shifts, influenced by all the factors that go into our social profile: demographic trends, economic developments, educational patterns, cultural diversity, even technology (think of how the availability of the automobile—both front and backseat—has changed the experience of adolescence). A quick historical review may help.

### **The Changing Status of Adulthood**

The status of adulthood in our society is simple and complex, obvious and obscure. At one level, it is a straightforward matter of age. Anyone who is over the age of 18 (or, for some activities, 21) is an adult, pure and simple. The process is automatic: one “gains” adulthood through simple endurance. If you live long enough, you cease being a child and become an adult. In legal terms, one could even be judged incompetent to manage one’s affairs but still remain an adult in this chronological sense.

At an equally basic level, adulthood can mean simply a state of biological maturity. In such terms, an adult is someone who has passed through the pubertal stage and is physiologically fully developed. As with the chronological meaning, this biological interpretation also is still common and largely accurate as far as it goes: to be an adult is, at least in a physical sense, to be grown up, mature, fully developed.

However, it seems clear to us that the matter has always been more complicated than either chronology (Kett, 1977; Meyrowitz, 1984) or biology (Bouwsma, 1976; Dannefer, 1984). These factors convey a sense of precision and permanence about the concept that simply ignores the process of social construction by which every culture imbues such terms with meaning (Ingstad & Whyte, 1995; Kalyanpur & Harry, 1999).

For example, historically we know that the beginning age for adulthood has been a surprisingly flexible concept even within the confines of Western culture (Modell, Furstenberg, & Hershberg, 1978). Philippe Aries (1962) has even argued that childhood itself, as a social distinction, was not “discovered” in Europe until the 16th century. Be-

fore then, he argues, children were treated as little more than the “miniature adults”—much like they were portrayed in medieval art (Aries, 1962). Adolescence, for example, was reported in a 16th-century French compilation of “informed opinion” as being the third stage of life, lasting until 28 or even 35 years of age (Aries, 1962). On the other hand, in colonial New England, legal responsibility for one’s personal behavior began at “the age of discretion,” which usually meant 14 to 16 years old (Beales, 1985), and many children left home for their vocational apprenticeships as early as age 10 or 12 (Beales, 1985; Kett, 1977).

At the end of the 19th century in Europe and America and continuing today, a period of postadolescent “youth” emerged, where children of the upper and middle classes (mainly males at first but now including females) could choose to postpone their adulthood by extending their professional training into their late 20s. As defines this role, the key distinction in this delayed adulthood was the extended status of economic dependency for these college students (e.g., Wohl, 1979). Taylor (1988) is even more specific: “Physically and psychologically adults, these individuals have not yet committed to those institutions which society defines as adult—namely, work, marriage and family” (p. 649). In many areas of the country, both urban and rural, this extended economic dependency continues to shape the cultural expectations of a “successful” transition to adulthood (Furstenberg, Cook, Eccles, Elder, & Sameroff, 1999; Magnussen, 1997). Most social historians seem to agree that, after a period of compression and inflexibility in the decades following World War II, the “acceptable” time span for transition from childhood to adulthood has become a mosaic of cultural and class variations (Elder & Rand, 1995; Kalyanpur & Harry, 1999; Modell et al., 1978).

What remains is a curious interaction of fixed periods of institutional transition (graduation, voting, legal status) with fluid patterns of family and cultural change (economic separation, living apart from parents, sexual activity, postsecondary education) (Mallory, 1995). As America grows more diverse, it seems likely that the traditional cultural markers of adulthood will only become more problematic and situational. Kalyanpur and Harry (1999), for example, point out that for many non-Anglo families, “it is assumed that the son will continue to live in the parents’ home, regardless of economic or marital status, and that the daughter will leave after marriage only to move in with her husband’s family” (p. 106). Turnbull and Turnbull (1996) report in their research that many Latino families stressed the values of unity and permanence in family relationships over “mainstream” values of independence and separation (pp. 200-201) when it came to goals for their children. At the same time, many children from poor families feel early pressures to contribute to the economic survival of the family and their own material well-being. In

many aspects of social life, teenagers engage in “adult” behavior at earlier and earlier ages (Furstenberg et al., 1999, p. 8).

Given this cultural and historical variability, how might we elaborate an understanding of adulthood that goes beyond age? How can we describe the social and cultural dimensions of adulthood? Finally, how do these social and cultural dimensions affect the experiences and opportunities of people with severe disabilities? We will address these questions by examining some of the dimensions of adulthood and their symbolic significance.

### **The Dimensions of Adulthood**

As Ian’s parents, we naturally thought it was important that Ian graduate from high school. More to the point, however, we felt it was extremely important that he participate as fully as possible in his high school’s commencement exercises. The graduation ritual itself seemed crucial to us. It took planning, coordination, cooperation, and compromise by a number of people to make that participation happen, but happen it did, as the picture of Ian in his cap and gown shows (Figure 16-1). Now, while Ian certainly enjoyed his graduation (especially the part where people applauded as he crossed the stage), we don’t know if he fully appreciated all the cultural symbolism attached to such events for many of the other participants. Missing the graduation ceremony would not have lessened the skills Ian had learned in high school, threatened the friendships he had forged, or worsened his prospects for a smooth transition from school to work. In other words, the importance of Ian’s participation in commencement was largely symbolic. It symbolized for us many of the same things that a son or daughter’s graduation from high school symbolizes for most parents.

Few events are as loaded with symbolism as a graduation ceremony. It is perhaps the closest our particular society comes to a formal rite of passage from childhood to adulthood. Of course, other societies and traditions might have other symbols equally powerful and not include anything related to ceremonies about finishing schooling. Much of what we are trying to capture in an understanding of adulthood occurs at this symbolic level of meaning. There are three important dimensions to this symbolic understanding (Table 16-1).

#### **TABLE 16-1**

#### **Dimensions of Adulthood**



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Autonomy:	Being your own person, expressed through symbols of:
Self-sufficiency:	Especially economic self-sufficiency, or having the resources to take care of oneself. Includes emotional self-sufficiency, or the ability to “make it” on one’s own. Marks a shift from economic consumption to consumption and production.
Self-determination:	Assertion of individuality and independence. The ability to assure others that one possesses the rational maturity and personal freedom to make specific choices about how to live one’s life.
Completeness:	A sense of having “arrived.” A shift from future to present tense. No more waiting.
Membership:	Community connectedness, collaboration, and sacrifice expressed through symbols of:
Citizenship:	Activities of collective governance from voting and participation in town meetings to volunteering for political candidates; expressing your position on issues with money, time, or bumper stickers; or recycling to protect the shared environment.
Affiliation:	Activities of voluntary association, fellowship, celebration and support from greeting the new family in the neighborhood with a plate of cookies to being an active member of the church, a participant in the local service or garden club, or a member of the local art museum.
Change:	Adulthood as an ongoing capacity for growth rather than the static outcome of childhood. Change occurs for adults as they change jobs, move to new apartments or houses, relocate to new communities, or go back to school to learn new jobs or hobbies. Change also occurs as old friends and family members move away and new friendships are formed.

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**The Dimension of Autonomy** Perhaps the most familiar and common symbols of adulthood in our society are those that convey a sense of personal autonomy. This dimension emphasizes the status of adulthood as an outcome, a com-

pletion. It is the *achieving* of adulthood that is the main focus; what happens throughout the adult years in terms of learning and growth or the physical changes that accompany aging are less the point. More specific features of autonomy can be seen in several aspects of life commonly associated with adulthood.

*Self-Sufficiency* One of the most often cited features of adulthood is an expectation of self-sufficiency. At the most fundamental level, this usually means economic self-sufficiency. Whether by employment, inherited wealth, or social subsidy, adulthood entails the belief that one has the resources to take care of oneself. This sense of self-sufficiency entails a transition from a primary existence of economic consumption and dependency to one of rough balance between consumption and production. Theoretically, even our welfare system works to preserve and enhance the self-sufficiency of individuals by providing temporary support and training.

However, self-sufficiency goes beyond this economic sense to also include elements of emotional adequacy. Adulthood usually has the sense of having the emotional as well as economic resources to “make it on one’s own.” People who are thought to whine about trivial complaints are often told to “grow up” or “quit acting like a baby.” Moreover, there are important gender differences in how our culture portrays emotional maturity. Still, in some sense or other, emotional competence in the face of life’s adversities is presented as an expectation for adults.

*Last year, Ian earned about \$3,500 in his job at the university. This annual income has varied over time from a high of \$4,500 to a low of \$3,000 as his responsibilities changed, as supervisors changed, and as other parts of his life took precedence. While this job and these earnings are important to his life as an adult, they do not begin to cover his living, to say nothing of his recreational, expenses. Even with the social service support dollars made available to him, the life he is creating for himself exceeds his available economic resources too much of the time. However, Ian has a job and social service dollars to support his efforts. Many people with severe disabilities have none, or what they do have are woefully inadequate. Poverty and disability have a long history, and self-sufficiency and poverty are incompatible.*

*One of the ongoing frustrations for Douglas and his family is that his employment has been episodic with sometimes long periods of unemployment. In the last few years, for example, he has worked alongside a local man named John who involves him . . . . <Margie, I need some examples here.>... But currently, he is again unemployed as John and a friend start up a new restaurant in a nearby town. Once the restaurant is operating smoothly, Douglas will join the team to assist with kitchen clean up, stocking, and other critical chores for any*

*small business.*

*Self-Determination* Self-determination and self-sufficiency are often treated as synonymous features of adulthood. However, while recognizing that the terms are closely related, we want to use the term “self-determination” to refer to a more active assertion of individuality and independence. An autonomous adult in this sense is someone who has the rational maturity and personal freedom to make specific choices about how to live his or her life. Autonomous adults make decisions and live with the consequences.

Certainly, from the perspective of childhood, this dimension of autonomy is probably the most anticipated. Self-determination involves all the freedoms and control that seem so oppressively and unreasonably denied as we suffer through the indignities of adolescence. We can live where we want, change jobs if we want, make our own judgments about what debts to incur and what risks to take, and make our own decisions when faced with moral dilemmas. We can even stay up late if we want or go shopping at 10:00 in the morning. However, these new privileges are quickly coupled with new responsibilities.

For persons with severe disabilities, the concept of self-determination is challenging and promising and has become a new focus of discussion and research (D. L. Ferguson, 1998; Priestley, 2001; Wehman, 2001; Wehmeyer, Agran, & Hughes, 1998). As a concept, self-determination could change not just what happens in the lives of people with severe disabilities but, more fundamentally, how we think about such things as services, supports, interventions, and outcomes.

One example of the role of self-determination and the challenges in understanding and interpreting it for people with severe disabilities first came to us wrapped in a Christmas Eve invitation.

*Ian invited us to his house for Christmas Eve for the first time about 6 years ago. Previously we had always celebrated holidays in our home, even after Ian moved into his own house. Of course, most families eventually face such a time when the location for holidays and other family rituals shifts from the parents' home to the children's. What is hard for us to unravel in our relationship with Ian, however, is just how this particular transitional invitation occurred. Did Ian somehow arrive at the determination that it was time to shift our holiday celebrations to his own home? Did his housemates, Robin and Lyn, who had been helping him can fruits and vegetables, make jam and breads, and decorate and arrange baskets for weeks, “support his choice” to invite*

*us over or shape his choice on his behalf? Did they somehow teach him how and why he might wish to request our presence at this holiday celebration? Since this first invitation, we have had many more—sometimes for holidays, sometimes just for an ordinary Wednesday or Friday, sometimes for lunch, sometimes dinner. Whatever Ian’s exact role in the decision to invite, it is clear that he enjoys having us in his house in a quite different way than he seems to enjoy visiting ours.*

For individuals whose communication skills are limited and for whom our understanding of their preferences and point of view can be incomplete, it is sometimes difficult to figure out when they are making choices—determining things for themselves—and when it is the interpretations of others that shape the outcomes. At the same time, it seems better to try to guess at another’s perspective and preferences than to ignore them altogether. At still other times, it may well be that no choice is made despite the opportunity.

*“Do you want eggs, pancakes, or bagels for breakfast tomorrow?” we asked Ian recently during an overnight visit. “Bagels,” was his prompt reply. “Do you want bagels, pancakes, or eggs?” Phil tried again, wondering if Ian was really listening and choosing. “Eggs,” Ian just as promptly replied.*

Over the years, we have tried various little tests like this to check whether Ian’s answers are choices or just his effort to support the conversational exchange by repeating the last thing he heard. Of course, questioning his apparent choices could seem unsupportive of his efforts to determine things for himself. Perhaps the admission that we question his response is as important as whether he is really choosing. These are the essential questions and dilemmas of self-determination for Ian and others with similar disabilities.

*Completeness* Perhaps the common element in all the features of adulthood as autonomy is a sense of completeness. What one gains with self-determination and self-sufficiency is clearly more than the imagined pleasures of doing totally as one pleases. Adulthood brings no guarantees of living happily ever after. Rather than the rewards of choosing well and wisely, adulthood seems only to finally offer the opportunity to make those choices, from silly to serious, on one’s own. Rather than working at learning all one needs to be an adult, one now finally *is* an adult, presumably putting to use all that learning and preparation. Adulthood has to do with the feeling of knowing how to act and what to do, such as what to order and how much to tip in any restaurant. Most of us have felt the pain of youthful uncertainty in “grown up” situations. We struggle to manage our youthful discomfort in the belief that each event will eventually bring the longed-for knowledge and confidence to cover all situations. In reality, of course, the com-

pleteness really comes with the ability to be comfortable with one's uncertainties.

Adulthood brings a sense of completeness—of preparation achieved—that is never there during childhood. The fact that many of us continue to feel uncertain in some situations well past middle age merely attests to the power of the notion of completeness to our understandings of adulthood. Even though as adults we continue to learn and grow, that learning is not in *preparation* for adulthood the way most of our learning was before achieving adult status. Even if we are unsure in some situations, it is not so much because we aren't prepared to handle it but rather because our knowledge and experience make the choice of action more ambiguous.

A continuing struggle for us is to make sure that Ian's adulthood is complete in this way. Even though he has continued to learn many things since high school graduation, we have tried to make sure that his learning of new skills or information is not a requirement placed on Ian by his supporters for achievement of adulthood. He is an adult even if he never learns another skill. It is a difficult balance to achieve. Ian (and all other adults) needs to be afforded opportunities to continue to learn and grow but without the trappings of preparatory training or schooling. If we think of life as a type of language, then adulthood as autonomy would seem to be a move from the future to the present tense.

**The Dimension of Membership** Sometimes it seems that we allow the dimension and symbols of autonomy to exhaust our understanding of adulthood. Adulthood in this view is essentially a matter of independence. This can create problems when we ask society to respond to all people with severe disabilities as “fully adult” since many are limited by their disability from demonstrating such independence in ways that are similar to how others without disabilities demonstrate them. Indeed, for many people, this limited independence is precisely what the label of “disability” means in the first place. However, we would argue that limiting our understanding of adulthood as “being able to do it by yourself” is problematic for all adults whether or not they have a disability. There is an equally important dimension in understanding adulthood that serves as a crucial counterbalance to the individualistic emphasis on autonomy. This dimension includes all those facets of adulthood that involve citizenship and affiliation and that must be supported by the collaboration and sacrifice of others. We collectively refer to these facets as the dimension of membership. If adulthood as autonomy is a move to life in the present tense, then adulthood as membership recognizes that life is plural rather than singular, communal as well as individual.

*Douglas lives in a small town in the family home. During high school he found the opportunity of*

*getting up and leaving class when the period ended to be an opportunity to be taken any time that the call of the activity in the gym was more appealing than what was going on in class. Waiting for a bell seemed silly when the decision could be made so much easier by him without the assistance of a bell. Expressing his self-determination in this way, however, was frowned upon by the adults and the “problem” of getting up and leaving class became one to be solved by the professionals. The classroom teachers had few ideas, but the resource teacher decided that finding some ways for Douglas to “buddy up” with some classmates might help. Soon a group of friends – one or more of whom were always in his class – simply looked out to make sure he got to the next place at the appropriate time. Invitations to movies, dances, and other social events followed and now, many years later, he still sees and spends time with the some of these same friends who are all members of the community.*

*Citizenship* Anthropologists have probably contributed most to our understanding of the communal aspects of adulthood in most cultures, including our own. They have described in detail the rituals and responsibilities that societies attach to adult status. In a very real sense, it is only with these rites of passage into adulthood that we become full members of our communities. In part, this involves an element of responsibility for others and the community in general. Voting and other acts of collective governance are the most obvious signs of this theme and perhaps seem the most daunting for some adults with severe disabilities.

*We have not pursued voting as a way for Ian to explore this aspect of membership, mostly because we fear that providing the assistance he would need might really just result in one of us having the advantage of two votes. However, there are other ways Ian can exercise community responsibility. Stuffing envelopes, for example, passing out campaign information, or expressing an opinion through yard signs are ways Ian can and does contribute to the political life of his community. Actively recycling by using his backpack instead of bags when shopping and expressing his political opinions on issues of accessibility with the “Attitudes Are the Real Disability” bumper sticker affixed to the back of his wheelchair are examples of ways in which Ian participates as a citizen of our community.*

*Affiliation* The communal dimension of adulthood is not only about a grudging performance of civic duties or even a cheerful altruism of civic sacrifice. An important aspect of communal adulthood lies in the various examples of voluntary association, fellowship, celebration, and support that adults typically discover and create. One of the most

common signs of adulthood, for example, is the intentional formation of new families and the extension of old ones. Through formal and informal affiliations, adults locate themselves socially as well as geographically (Figure 16-2). You might live on the east side of town, belong to the square-dance club, attend the Catholic Church, and have a spouse and two kids. We might live in a downtown condo, belong to the library patrons' society, participate in Community Theater, and volunteer at the local rape crisis center. The particular array of affiliations can differ dramatically. However, in the aggregate, those affiliations help define a community just as the community, in turn, helps define each of us as adults. Through their affiliations, adults support and define each other.

The definitional power of our affiliations seems to us very true for Ian and other adults who require similar supports. Ian's life tends to reflect the people in his life. Right now, his two primary support people like to camp, give big parties, and garden. So Ian does, too. Moreover, Ian's community of Eugene, Oregon, is one that prizes such outdoor activities, and so there are many groups and opportunities that encourage these hobbies. When Ian was in his early 20s, dancing and pool were favorite pursuits of his supporters, and Ian obligingly enjoyed these activities just as much. At the same time, Ian has his own long-standing hobbies. He finds the lights and sounds of casinos especially enjoyable. Here as well, it is not the singular pursuit of winning or losing that Ian enjoys so much as it is all of the people and activity filling the casino with noise and hubbub. All of us in Ian's life have had to find ways to join in the occasional excursions to nearby casinos, while keeping a close eye on the dollar amounts won and – more likely – lost. (Figure 16-3). Not only must Ian join in the interests and affiliations of friends and family, they must also join Ian in some of his choices as well.

*Lenny was one of those boys in high school who made sure that Douglas went from one class to the next only when the bell rang. He is married now and with his own children, but he and Douglas still see each other regularly. Sometimes Douglas helps around Lenny's house splitting wood or doing yard work and gardening. Sometimes they go out to the bar or other events. Lenny's cousin owns a garage and sometimes they both go over to help out – Douglas being in charge of finding the right tools and making sure everything gets put back in its correct place. Douglas is a bit finicky about things being in their proper place whether it is in his parents' kitchen or the garage and it is one of the personal traits that probably helps him build and grow his affiliations in the community through his friends and their friends.*

**The Dimension of Change** We said earlier that adulthood as autonomy could be described as a move from the fu-

ture to the present tense. The dimension of adulthood as membership shows that the description requires a plural rather than a singular construction. Let us follow the logic in this final dimension of adulthood and argue that a dynamic approach to life demands that adulthood must finally be understood as a verb, not a noun. In the biological sense, adulthood may indeed represent a developmental maturity; in a social and psychological sense, it can also represent phases of continued growth.

Of course, this aspect of adulthood has been the focus of increased attention in developmental psychology since the seminal work of Erik Erikson (1950) on the eight “crises” or stages of the life cycle, four of which occur in adulthood. Subsequent psychologists have variously refined and revised this work (Erikson & Martin, 1984; Levinson, 1978; Vaillant, 1977). Sociologists and historians have added an important sociocultural perspective to these stages within the life span (Dannefer, 1984; Elder, 1987; Hareven, 1978). In general, however, these developmentalist writers help us understand that adulthood has its own stages of growth, change, and learning. It is a period of both realization and continued transition.

As with most scholarly “discoveries,” the understanding of adulthood as full of change and development is neither new nor scholarly. As a theme, it runs through some of our richest traditions. One theologian (Bouwmsma, 1976) has identified the Judeo-Christian tradition as one in which adulthood “implies a process rather than the possession of a particular status or specific faculty” (p. 77). He goes on to describe the key element for adulthood in this tradition not as the completion of growth but as the “capacity for growth” (p. 81). However, it is perhaps the Confucian tradition that best captures this understanding of adulthood with its depiction of life as a journey in which one is always “on the way.”

*Ian is now 40. He seems to have transitioned, along with his housemates, into the very beginnings of the ever-changing span of time we call “middle age.” He is a different person than he was at 21. His tastes in music are still eclectic, but he seems to enjoy visiting his parents and singing along to old Paul Simon, Beatles, or Simon and Garfunkel CDs more than he did 7 or 8 years ago. He’s gained some weight, and we’ve been told he has a few early gray hairs (we haven’t spotted them yet). He’s getting a little arthritis in his knees. More than changes in his appearance, however, he approaches his 40s with a different demeanor. He can be serious or consoling when the occasion demands, although he might not describe the emotion in those terms. He has experienced the death of grandparents, lost friends and support workers, and learned how to be alone in ways that are dif-*



*ferent than when he lived with us.*

*His parents have moved to work in a new state. Although Dianne is still working in Eugene part time and is around part of every month, Phil visits only a few times a year and talks to Ian a couple of times a week by phone. These changes mark a new phase in all our lives. We all miss living close to each other as Ian expresses clearly each time he meets one of us at the airport with smiles, enthusiasm, and sometimes flowers. We worry about the distances, but for now Ian's adulthood is secure enough, even with all the continuing challenges, to make this kind of change possible for all of us.*

For many people with disabilities, these three dimensions of adulthood occur only partially, often as approximations of the symbols the rest of us use to identify others and ourselves as adults. Table 16-2 illustrates some examples of these symbols that are present in many adult lives, though not in as many adult lives of people with disabilities. If we only assess the symbols we each can claim, however, we may make the mistake of denying the status of adulthood to people with disabilities. Symbols are important, but they are not the whole story. One way we evaluate our success at supporting Ian's adulthood is to examine periodically just how each of these dimensions is visible in his life. How does the daily round of Ian's life reflect ways of becoming a unique member of our community? Are his activities, affiliations, and ways of participating varied? Do they change over time? Do they reflect a changing understanding among his circle of family, friends, and supporters of Ian's own preferences and choices? We'll return to these questions later with examples that might help you see how these dimensions of adulthood can apply in the life of a person with severe disabilities. First, however, let us examine more completely why these notions have been so difficult to apply to this group of people.

**TABLE 16-2**

**Symbols of Adulthood: Some Examples**

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**Symbols of autonomy**

- Having a source of income, a job or wealth.
- Making your own choices, both the big important ones and the little trivial ones.
- No more waiting for the privilege of doing what you want, how you want, when and with whom you want to do it.

### **Symbols of membership**

- A voter registration card.
- Membership cards for organizations and clubs.
- An appointment calendar and address book.
- Season tickets, bumper stickers, charitable contributions of time and money.

### **Symbols of change**

- Marriage
- Acquiring new hobbies
- Children
- New jobs and homes
- Learning new skills
- Old friends

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## **DENYING ADULTHOOD**

If the meaning of adulthood involves the dimensions of autonomy, membership, and change, then how have those dimensions affected our understanding of adults with severe disabilities? There are undeniable improvements over the past decade in the movement of people with intellectual disabilities into community-based jobs and residences (Blanck, 1998; Prouty, Smith, & Lakin, 2002). However, the evidence of continuing problems in the quality of life for many of these individuals is apparent even to the casual observer. Most states continue to have long waiting lists for residential and employment opportunities. According to one poll (Louis Harris and Associates, 2000), between 65% and 70% of people with disabilities are unemployed (Wehman, 2001). As of 2002, almost 60,000 individuals were estimated to be waiting for residential services outside their family homes (Prouty et al., 2002). Although the number of people with developmental disabilities residing in large private or public institutions has dramatically declined over the past two decades, the federal government still spends some \$5.6 billion (for fiscal year 2000) to keep

people in large congregate care facilities (Braddock, Hemp, Rizzolo, Parish, & Pomeranz, 2002). In other words, although only 10% to 15% of people with developmental disabilities receiving residential services (not including individuals sharing a home with a relative) lived in large, public institutions, almost half (45%) of the federal MR/DD Medicaid spending went to support those individuals (Braddock et al., 2002; Lakin, Prouty, Polister, & Coucouvanis, 2003). For over 15 years, evidence has mounted for the economic and social benefits of supported employment for adults with developmental disabilities. Yet unemployment and segregated workshops and day programs still dominate the vocational services offered (Blanck, 1998; DeLio, Rogan, & Geary, 2000; Wehman, 2001). For individuals with severe disabilities, in particular, this empirical evidence of a poor quality of life must also be understood in a historical context.

If you examine the history of adulthood for people with severe disabilities, you find a story not only of symbolic deprivation but also of economic deprivation. Indeed, at the heart of our discussion is the belief that the two are inextricably related. Symbols of adulthood accompany the practice of being an adult. Or, to reverse the logic, the denial of adulthood to people with severe disabilities has been symbolic as well as concrete. Recent movements to recognize the full range of rights and responsibilities of adults with severe disabilities can best be understood in light of this history of denial. Table 16-3 summarizes some of the symbols of denial of adulthood across the dimensions discussed next.

**TABLE 16-3**

**Symbols of Denial of Adulthood: Some Examples**

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**Unending childhood**

- Childish, diminutive names like Bobby and Susie.
- Enforced dependency that permits others to make all important choices.
- Few life changes.

**Unfinished transition**

- No more school but no job, home, or affiliations in the community.

- Rituals for ending but not for beginning.
- Acquisition of visible but empty symbols like beards and pipes but no jobs, homes, or community affiliations.

### **Unhelpful services**

- Clienthood: A focus on remediation and readiness determined through the mechanisms of professional preciousness.
- Anonymity: Service standards and procedures that overwhelm individuality and uniqueness.
- Chronocity: The professional decision to deny lifelong change because the client is insusceptible to further development.

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### **Unending Childhood**

Wolfensberger (1972) not only helped popularize the principle of normalization as a basic orientation for human services but also deserves credit for raising our awareness of the symbolic dimensions of discrimination and stigma in the lives of people with severe disabilities. In particular, he helped highlight how society referred to people with mental retardation in terms and images that suggested a status of “eternal childhood.” Nearly 30 years later, it is still frustratingly common to hear adults with severe disabilities described by the construct of “mental age”: “Johnny Smith is 34 years old but has the mind of a 3-year-old.” In an interview we did some years ago (P. M. Ferguson, Ferguson, & Jones, 1988), an elderly parent of a 40-year-old son with Down syndrome described him as a sort of disabled Peter Pan: one of the “ever-ever children.” “This thing about normalizing will not happen ... they’ll always be childlike” (p. 109).

Fortunately, the myth of eternal childhood as the “inevitable” fate for people with severe disabilities is much less powerful than it was 10 or 20 years ago. We like to think that today’s generation of young parents is less likely than our generation to learn from professionals that their sons and daughters are “ever-ever children.” Increasingly, it seems that both professionals and the general public are aware of the stigmatizing assumptions built into childish terms of reference. Appearance and activities are more and more likely to avoid the most obviously childish examples (e.g., adults playing with simple puzzles or toys, carrying school lunch boxes to work). We are gradually moving away from our infantilizing images of the past.

Of course, if symbols are the only thing to be changed, then the true movement to adulthood will still be stalled. We remember working at a large state institution for people with severe disabilities some 25 years ago. This institution closed in June 1998, but at the time, a number of people who worked there had apparently gotten only part of the message about treating people as adults. As a result, over a period of months, all the adult men on one ward grew beards and smoked pipes. Nothing else changed in their lives to encourage their personal autonomy, much less their membership in the community. The beards and pipes were simply empty symbols of adulthood that had no grounding in the daily lives of indignity and isolation that the men continued to lead. Alternatively, allowing someone the choice to risk his or her health by not wearing a seat belt in the car or by eating three large pizzas for dinner in the name of autonomy and adult independence also misses the point, resulting instead in a limitation of adulthood, perhaps quite literally if that person's health is threatened by such risky choices.

*Even at 40, Ian might choose to watch cartoons and always choose to drink chocolate milk or any number of other choices that might be more typical of a young child. Once in a while, these choices are fine. But as a steady diet, such choices do not communicate the full range of options most adults enjoy. Part of truly supporting Ian's adulthood is making sure he has enough experience of lots of different options to make adult decisions. He still does choose chocolate milk, but probably more often now, he chooses Dr. Pepper or a beer. And his taste in beer has grown more sophisticated in the past decade. He even enjoys wine more than he used to. The point is not so much to deny revisiting the preferences of childhood but to create the many more varied choices of adulthood as just as frequent options.*

### **Unfinished Transition**

An important part of the move away from the unending childhood view of severe disability has occurred in the increased programmatic attention paid to the transition period from school to adult life (Jorgensen, 1998; Wehman, 2001; Wehmeyer, 2001; Wehmeyer, et al., 1998). This focus on transition has certainly clarified the right of people with severe disabilities not to remain forever imprisoned by images of childhood. It has led to a heightened awareness on the part of the special education community that *what happens after a student leaves school is perhaps the most crucial test of how effective that schooling was*. In terms of program evaluation, the emphasis on transition planning in the schools has clearly identified adulthood as the ultimate outcome measure for the process of special education.

However, as a cultural generalization, an escape from unending childhood has not yet meant an entrance into full-fledged adulthood for many people with severe disabilities. Instead of eternal childhood, we see their current status as one of stalled or unfinished transition: a “neither-nor” ambiguity in which young people with severe disabilities are no longer seen as children or yet as adults. As with adulthood itself, however, transition too can be viewed symbolically. It is in this symbolic sense that people with severe disabilities can become embedded in a permanent process of incomplete transition.

Several scholars have suggested the anthropological concept of liminality as most descriptive of this situation (Murphy, Scheer, Murphy, & Mack, 1988; Mwaria, 1990). Liminality refers to a state of being when a person is suspended between the demands and opportunities of childhood and adulthood. Many societies use various rituals of initiation, purification, or other transitions to both accomplish and commemorate a significant change in status. In many cultures where these rituals retain their original intensity, the actual event can last for days or months. During such rituals, the person undergoing the process is said to occupy a liminal (or “threshold”) state. According to one author,

*People in a liminal condition are without clear status, for their old position has been expunged and they have not yet been given a new one. They are “betwixt and between,” neither fish nor fowl; they are suspended in social space without firm identity or role definition.... In a very real sense, they are nonpersons, making all interactions with them unpredictable and problematic. (Murphy et al., 1988, p. 237)*

For too many adults with severe disabilities, one could say the transition to adulthood is a ritual that once never began and now begins but seldom ends. Instead, they remain on the threshold of adulthood in a kind of permanent liminality—“suspended in social space.”

We see this liminality in the kinds of social responses to adults with severe disabilities that perpetuate social isolation in the name of autonomy. Professionals who tell parents they need to “back off” from involvement in their newly adult son’s or daughter’s life so that they can begin to build their own separate life apart from the ties of family and home sometimes end up isolating the new adult by removing the most effective advocates for an expanded membership in the community. Parents and professionals who conspire (usually with purely benevolent intentions) to create a facade of independence for adults with severe disabilities by allowing them trivial, secondary, or coerced

choices instead of true self-determination (Knowlton, Turnbull, Backus, & Turnbull, 1988) trap adults in the isolation of liminality in another way.

In still other instances, adults are given a plentiful supply of token affiliations and social activities with no attention to the symbols of self-sufficiency represented by a real job with real income, making the illusion incomplete in yet another way. Such an ambiguous social status will continue to frustrate individuals in their efforts to define themselves as adult. Society in general will continue to feel uncomfortable in the presence of such people, not knowing how to respond.

*Ian's own transition seemed at risk of an extended liminal status for the first few months after graduation. He continued to live in our home, and his only "job" was a volunteer job that he had begun when in high school. His personal agent and personal support staff created a schedule of personal and recreational activities to fill his days. While Ian certainly enjoyed this round of activity, it felt to us, and we think to him as well, like a kind of holding pattern. He was waiting for his chance to enter the routines and responsibilities of adulthood. The "meantime schedule" of activity was a substitute and one that, in the end, did not last long. We'll have more to say about Ian's adult life later and how his daily and weekly routines simply are his life and substitute or wait for nothing.*

### **Unhelpful Services**

Although the special education system must share part of the blame for unfinished transition, much of the responsibility must fall on an "adult" service system historically plagued with problems of poor policy, inadequate funding, and ineffective programs (P. M. Ferguson & Ferguson, 2001; P. M. Ferguson, Hibbard, Leinen, & Schaff, 1990; Smull & Bellamy, 1991). There are significant exceptions to this generalization across the domains of residential programs (Howe, Horner, & Newton, 1998; Taylor, Bogdan, & Racino, 1991), employment support (Mank, Cioffi, & Yovanoff, 1997), and leisure and recreation (Anderson, Schleien, & Seligmann, 1997; Dattilo & Schleien, 1994; Germ & Schleien, 1997), but for far too many, the promise of adulthood remains an unfilled promise.

Many analysts of the social service system continue to point to fundamental inadequacies in adult services (Bé-rubé, 2003; Drake, 2001; Ferguson, 2003; Fleischer & Zames; 2001; McKnight, 1995). Although each of these analyses has its own list of problems, they all include some basic complaints. We will briefly mention three of these is-

issues that correspond to the three dimensions of adulthood we have already set forth. These three issues are (a) clienthood, (b) anonymity, and (c) chronicity.

**Clienthood** The traditional service system promotes “clienthood” rather than adulthood. Dependency unavoidably fosters the role of clienthood either explicitly or implicitly, and dependency is the status of many individuals “served” by the traditional service system. The role has many versions, but perhaps the most familiar is that which imposes a model of medical or behavioral deficit as the dominant rationale for service decisions. In this version, the essential orientation for service delivery is that the individual with the disability has something that needs to be cured or remediated. Just as patients are expected to follow the doctor’s orders and take the prescribed medicine, so are people with disabilities expected to follow their “individual habilitation (or support) plans,” work hard to improve themselves (Bickenbach, 2001; Drake, 2001; McKnight, 1995; Phillips, 1985), and abide by the suggestions of their designated professionals (e.g., case managers, job coaches, residential providers).

This dependency is perhaps most familiar in those aspects of the welfare system (e.g., Supplemental Security Income, Social Security Disability Income, Medicaid) that can unintentionally create economic disincentives to vocational independence. But it is equally powerful at the more personal level through a tendency that Sarason (1972) has called “professional preciousness.” Professional preciousness refers to the tendency of professionals to define problems in ways that require traditionally trained professionals (like themselves) for the solution. Thus, case managers sometimes define a client’s needs according to what the system happens to provide (Drake, 2001; Taylor, 2001). Opportunities for meaningful employment are overlooked or unsought unless they have been developed through the proper channels of certified rehabilitation professionals rather than untrained but willing coworkers (Nisbet & Hagner, 1988). Those who find the penalties too high for participation in such a system can “drop out” but only at the risk of losing all benefits (especially health care) and without official standing as “disabled” at all (P. M. Ferguson et al., 1990). By limiting the avenues for achieving jobs, homes, and active social lives to the “disability-approved” services offered through the formal service system, clienthood undermines autonomy (P. M. Ferguson & Ferguson, 2001; Williams, 2001).

We realize we have drawn a pretty bleak picture. Our point is not that that all public policy is somehow bad or that it does not sometimes contribute in very real ways to realizing adulthood for many with disabilities. We are saying that people with severe disabilities will more often than not suffer less rather than more at the hands of the formal



system. We and many other families have struggled to “tweak” and bend the demands of the formal system to allow it to better meet the needs of our sons and daughters. Our successes, when they occur, best serve to make our point that we need a system that doesn’t require extraordinary effort to resist the clienthood, anonymity, and chronicity that too often describe our current system of service.

*We have strived to create options for Ian that use the social service system but reject this status of clienthood, at least from Ian’s point of view and, perhaps more important, from the point of view of his direct supporters. Although Ian’s living situation is possible because of the official funding category of “supported living” and his job support dollars are provided through the category of “supported employment,” we have redirected these dollars from the familiar residential or vocational programs to a process that allows Ian, his family, and supporters to directly decide how to use these dollars. Along with a small number of friends and colleagues, we operate a nonprofit organization that does not decide for Ian or the three others we are currently also supporting but rather manages the paperwork, rules, reports, and budgets that permit Ian and those most directly involved in his life to direct how the support dollars are best used to support his adulthood. Our collective efforts to support Ian’s definition of his own life have allowed us to meet the necessary rules and regulations but protect Ian and his supporters from having to attend to them constantly. It has become the responsibility of Ian’s personal support agent to make sure that the penalties of participation in the service system are minimized so that Ian may develop his own adult identity apart from that of social service system client.*

**Anonymity** The traditional system not only promotes dependency for many but also creates a kind of bureaucratic isolation in which procedures replace people and standardization overwhelms context. Certainly this is partly and simply a function of the size of the programs and the numbers of people involved. However, it goes beyond this to a style of centralization and control that pursues efficiency above all else. This style often leads to situations of sterility and isolation in programs that are ostensibly intended to increase a person’s social integration. The need for efficient purchasing and supply can lead to so much similarity in the possessions and activities of clients that the individual becomes swallowed up in a collective that diminishes each member’s uniqueness. It seems unlikely that the individuals in a dozen group homes and apartments operated by the same supported living agency all like the same brand of ice cream, prefer the same laundry detergent, and choose the same color paper napkins, for example.

An even more powerful example involves the types of relationships many people with severe disabilities experi-

ence. One thing that seems important to the social relationships and friendships that most of us enjoy is “knowing each others’ stories.” The very process of a developing friendship usually involves learning about each other through the stories of experiences and history shared in conversation.

*When people enter Ian’s life, we support the developing relationship by sharing much of Ian’s story for him. If he lived in a community residential program, however, the constant turnover of staff and the demands for confidentiality might so limit what others know about his life that he is rendered virtually anonymous except for what can be readily observed and directly experienced.*

**Chronicity** The final barrier that seems an unavoidable facet of the traditional support system is something we term “chronicity.” Chronicity is the officially delivered, systematic denial of lifelong change and growth. Chronicity is created by professional pronouncements that someone or some group is unsusceptible to further development. Again, this barrier results from the dominance of what might be called a “therapeutic model” in the overall design of services. For those who “respond to treatment” in this model, there is a future of more treatment, more programs, and more clienthood. However, for those whose disability is judged so severe as to be beyond help (e.g., “incurable,” “hopeless,” “ineducable”), there is a professionally ordained abandonment (P. M. Ferguson, 2002). The person becomes “caught in the continuum” (S. Taylor, 1988), whereby expansion of adult opportunities is denied as premature while commitment to functional improvement is abandoned as unrealistic. For example, even service reforms such as supported employment that were initially developed specifically for people with severe disabilities have been denied to people with the most severe disabilities, who are judged to be “incapable of benefiting” from vocationally oriented training (D. L. Ferguson & Ferguson, 1986; P. M. Ferguson, 2002). In this orientation, the system presents full adulthood for people with severe disabilities as something that must be “earned,” a reward handed out by professionals to people judged capable of continuing to progress. Failure to progress in the past justifies compressed opportunities in the future.

### **The Dilemma of Adulthood**

All this leaves those of us who wish to see the promise of adulthood fulfilled for people with severe disabilities with a frustrating dilemma: How can we help people with severe disabilities gain access to the cultural benefits of community membership and personal autonomy associated with adulthood without neglecting the continued needs for adequate support and protection that did not end with childhood? How can we achieve this in the context of the cur-

rent service system that can be more unhelpful than helpful? Let us offer a fairly minor example of this dilemma.

*If someone asked Ian if he wanted to watch a Beavis & Butthead video or 60 Minutes, he would almost certainly choose the Beavis & Butthead. It's lively, has lots of odd (sometimes rude) noises, and has plenty of music.*

*An Ed Bradley interview just does not match up.*

Concerned as we are with Ian's adult status, should we honor his choice as an autonomous adult and turn on the video even though we know it is an activity commonly associated with younger folks? Or should we override his choice in the belief that in this case the outcome (i.e., watching more adult entertainment) is more important than the process (i.e., allowing him to independently choose what he watches)? Perhaps we should not offer him the choice in the first place, confident that we will select a much more age-appropriate program. In the long run, we might argue, this will enhance Ian's image and expand his opportunities for affiliation and membership in a community of adults. Or is it okay to watch the Beavis & Butthead video once for every two or three times he watches Mike Wallace? Finally, we might look at this example of his viewing habits as an area of learning for Ian and emphasize the dimensions of change for him. In so doing, we might honor Ian's choice for now while simultaneously exposing him to more options that might be equally appealing but less childish (perhaps MTV as a compromise between Mike Wallace and Beavis).

Excessive emphasis on symbols of autonomy might actually diminish a person's access to membership symbols. Having only a volunteer job is not the same as volunteering your free time after work at a paid job. Making sure a young adult lives apart from previous family and friends in the pursuit of an image of self-sufficiency, for example, may restrict the adult's involvement in activities and groups that those very family and friends might help to access.

Similarly, excessive emphasis on change might perpetuate the liminal position of being permanently stuck on the threshold of full adulthood, spending one's days in endless preparation for life instead of actually living it. This is perhaps most common for those young adults who leave the preparatory experience of schools only to find themselves in a day program or residential service that continues a readiness training focus. Many young adults with severe disabilities still leave high school for the continued preparation of work training programs and sheltered workshops where many will labor for 30 to 40 years in a parody of productivity. We wonder how many adults "retire" from such programs when they reach their 60s without ever "graduating" to real jobs.

*Douglas and his family have struggled with finding him real work since school ended. Services in his rural part of Atlantic Canada are quite limited and Douglas' support needs are significant despite his skills. One of the first jobs involved a family-operated business growing sprouts that were then sold to local grocery stores. Douglas learned to assist in growing the sprouts, but really liked better packing the sprouts for sale, loading the van and delivering them to a round of local shops. Some of the people he got to know through this job not only still know him, but make his daily presence in the community more secure and socially networked as he still sees and engages with them. The sprout business became a casualty of development. The smaller groceries gave way to one or two larger grocery chains that preferred to import their produce from large distributors in Ontario instead of purchasing from local farmers – and sprout growers. The business eventually became financially untenable and Douglas experienced the first of what would be several periods of unemployment.*

While sheltered workshops are less likely to include periods of unemployment, indirectly, such one-dimensional service offerings can deemphasize the importance of social reform to accommodate a broader range of acceptable adult behavior. Instead, we believe that a full understanding of the multidimensional aspects of adulthood in our tradition and culture allows a more productive and flexible approach to the dilemma of balancing self-sufficiency with support and social accommodation with personal development.

*Ron works at the same university we have for many years. He lived in a large institution for people with mental retardation until he was in his 40s. Now he works delivering mail from the dean's office to other parts of the college. Ron doesn't talk and has a history of lashing out at himself and others when he is confused or unclear about what is happening to him. When you encounter him in the mail room and say "hello," he will often respond by withdrawing, avoiding eye contact, and making his own unique sounds. To many people, these responses seem like he is retreating and uncomfortable with these interactions. Over time, however, those who persistently greet and interact with Ron realize that these responses are an acknowledgment and, perhaps, recognition of a familiar face.*

For us as parents, it seems that the professionals have done a good job of convincing society to recognize the importance of a transition from childhood but have not fully discovered what that process should be a transition to. We are, as it were, still in mid-journey on the trail toward adulthood for people with severe disabilities. As profes-

sionals, it seems to us that our field has not adequately understood the complexity of the journey or the character of its destination. Without such an understanding, the processes of achieving adulthood—symbolically or otherwise—for people with severe disabilities will never reach a conclusion.

Having said that and having explored the dilemma of adulthood for people with severe disabilities, we must now turn to the good news. Answers are emerging. Perhaps we have moved past the midpoint of our journey, at least for some adults with severe disabilities. Our last section will explore some of these developments after a brief summary review.

## **ACHIEVING ADULTHOOD**

To summarize, the promise of adulthood in our society should be more than a job, a place to live, and being on one's own. A full understanding of the meaning of adulthood must look at the structure of symbols and imagery that surround this culturally defined role. In looking, we found that we could organize that symbolic structure around the three dimensions of autonomy, membership, and change. We elaborated the dimension of autonomy into three elements (self-sufficiency, self-determination, and completeness) and membership into two elements (citizenship and affiliation). Then we discussed the ways in which our current service options often tend to deny full participation in these dimensions. Even though some of the symbols of autonomy, membership, and change might be attempted, too often the result for persons with severe disabilities is really an experience of unfinished transition or unhelpful services.

Despite recent and helpful moves within the field of special education and disability services to focus on the importance of the transition process from school to adult life, we argued that most adults with severe disabilities remain on the threshold of adulthood in the fullest sense of substantive participation in both the symbols and the substance of multidimensional adulthood. An unhelpful service system helps perpetuate this unfinished transition by encouraging dependency, social isolation, and personal chronicity. This leaves us with a dilemma of how to surround people such as Ian with resources that recognize their needs without denying their adulthood. The good news is that it really is possible. The bad news is that it is present for only a few so far. There is still much to do.

We believe that the solution to the dilemmas we have raised about adulthood lies in the merger of a reformed support system with a multidimensional understanding of adulthood. In this section, we first outline some of the key

themes of this new paradigm for support services that respond to the barriers to adulthood that the current system continues to create and maintain despite these new efforts. Next we will look at how these themes are starting to emerge in terms of the three dimensions of full adulthood that we have discussed. We think that, taken together, these expanded versions of support and adulthood provide an inclusive approach to achieving a high quality of adult life for all people, even those with the most severe disabilities or intensive support needs. Finally, we freely admit that probably nowhere in our country could one find all the elements of this new approach in place, fully functioning. However, we also believe that each of the elements does exist somewhere for some people right now, and for some, we are beginning to achieve several elements. There is increasing reason for optimism that systemic change is starting to occur. The challenge we face is “simply” to fill in the gaps.

### **The Concept of Support**

The significant reforms of the past 25 years in developmental disabilities have occurred mainly under the banners of deinstitutionalization and normalization. We need to recall the massive shift of people from large, segregated settings to more community-based arrangements that has occurred in less than 3 decades (Braddock et al., 2002; Lakin et al., 2003; Prouty et al., 2002). In the past few years, even some of the money to support these people has made a similar shift from institution to community (Braddock et al., 2002). However, while only partially achieved, normalization and deinstitutionalization now need to be joined (or perhaps even replaced) by a new banner if we are to revitalize the move toward continued restructuring of policy and practice (P. M. Ferguson, Ferguson, & Blumberg, 1997; Linton, 1998; McKnight, 1995; Nerney, 2000; O'Brien & Murray, 1997). It is increasingly possible to see the outline of an effort to move beyond the perceived limitations of deinstitutionalization and normalization as policy guidelines to an emphasis on support and self-determination.

The central feature of this new, and admittedly sporadic, effort to radically reorient adult services is an expanded understanding of the concept of “support” and its relationship to self-determination. One way of summarizing the conceptual model that seems to govern this effort is “supported adulthood.” The supported adulthood approach is the result of an inductive process. Its unifying vision has emerged out of disparate reform initiatives from across several service domains, including supported employment, supported living, supported education, supported recreation, and supported families.

### **What Is New About Supported Adulthood?**

Supported adulthood is more than a simple commitment of the field to redress past institutional wrongs by eliminating segregated options. It is also more than an attempt to make people “appear” normal. The central theme is in the expanded interpretation of what is and is not supportive of a full adult life in the community. The common purpose is in the effort to recognize a dual sense of independence and belonging as the most basic benefits of social support programs. This enriched notion of “support” has indicated a way out of the conceptual dilemma whereby people with disabilities had to either earn their presence in the community with total independence and self-sufficiency or be inserted there with the type of bureaucratic arrogance so common to social welfare programs. In either case, the result was all-too-clustered isolation associated with the overlapping problems of perpetual clienthood and excessive individualism already described. The image of the 10-bed group home comes to mind, with residents separated from their neighbors simply by the size and regimentation of their house. It became a place of work for direct care staff rather than a home where people lived. All too often, adults with severe disabilities were in the neighborhood physically but not socially; present but not truly “part of” their communities.

What is new in the notion of supported adulthood is a guiding commitment to participation and affiliation rather than control and remediation. “Support” becomes an adjective, modifying and enriching an adult’s capacity for participation in and contribution to his or her community. Support cannot be a predefined service available to any who meets eligibility criteria. The real message of initiatives such as supported employment and supported living is—or should be—that all people do not have to be totally independent in terms of skills or fully competitive (or even close) in terms of productivity to be active, growing, valued adult members of their communities.

### **Components of Supported Adulthood**

There are at least five features of this expanded approach to support for adults with severe disabilities and their families: (a) natural contexts, (b) informal supports, (c) user definitions, (d) local character, and (e) universal eligibility.

**Natural Contexts** The traditional welfare approach to services for people with severe disabilities has been the creation of special settings, with special staff, and separate bureaucracies (e.g., institutions, self-contained schools, and sheltered workshops). Part of the economic irrationality of many of the current approaches is that funding tracks continue to direct financial resources into these settings even as the field increasingly recognizes their inadequacies (e.g., the continuing institutional bias of federal Medicaid programs; see Braddock et al., 2002). Certainly, the situation is improving, as states have finally tipped the balance in financial support toward community programs. The growing

use of Medicaid waivers for community support (Braddock et al., 2002) has allowed the federal government to work more closely with states in removing policy barriers that previously kept Medicaid dollars from flowing into progressive community settings. All these trends show a growing appreciation for the value of the natural context as the location of choice for people with disabilities regardless of the domain of life being discussed.

Supported adulthood requires a reliance on natural contexts in the design and location of its supports. Support must become an adjective or adverb that “modifies” an existing, natural setting rather than meaning the creation of a separate one. This shift directly challenges the traditional belief that the more intensive the support needs, the more segregated the setting had to be (S. J. Taylor, 1988, 2001). Instead, the focus on natural settings allows the intensity of support to be truly individualized from context to context instead of programmatically standardized along an arbitrary service continuum (American Association on Mental Retardation, 2002).

The supported adulthood approach brings progressively intensive support to those individuals who need it without abandoning the community setting. The assumption driving the design of services within this approach is that vocational “programs” for people with severe disabilities should occur in those settings within the community where work naturally occurs, not in specially created sites or segregated settings (Mank, 1996). Homes should be in neighborhoods where other people live (P. M. Ferguson et al., 1997; Walker, 1999). A preference exists for the generic service instead of the specialized one whenever possible. The appeal of natural contexts, then, is twofold: it returns to a reliance on the community setting, thereby combating the isolating tendencies of “specialized” programs, and it encourages independence by placing people outside the “protected” environment of segregated programs.

*A shift to natural contexts first began for Ian during his last years of high school. One of the community jobs he explored—doing laundry at the local YMCA for the next day’s fitness enthusiasts—continued as a volunteer job that earned Ian a free membership for a couple of years after he finished school. Now all his life and supports occur in natural contexts. He lives in a home in a typical neighborhood much like his parents (see Figure 16-4). His job for the past 12 years is with the university food service part of the student union and involves him traveling all over campus (Figure 16-5). But even beyond these major components of his life, being part of the natural context over the years—for living, work, and recreation—has resulted in the emergence of natural supports, such as patrons who are used to Ian and his paid support person coming to the pub on High Street and who lend a hand with this chair when he occasionally needs to use the bathroom that is up a couple of steps or*



*the concertgoers who are familiar with Ian's attendance at such events and let him break into the intermission refreshment line to join them and say hello.*

**Informal and Formal Support Resources** A second, related element is the recognition that support should be informal as well as formal. This element directly challenges the problems identified with the traditional client-based role for individuals with severe disabilities and their families. In practical terms, informal—or natural—support is what people who are not paid for the “services” provide (e.g., emotional support, practical assistance, moral guidance) like the community members in the previous example. As we mentioned earlier, as long as a professional client model governs the provision of adult developmental disability services, then support, by definition, will be organized and controlled by the formal service system. Efforts that most closely adhere to a supported adulthood approach are always bureaucratically “thin” and not necessarily oriented toward direct service provision. Such efforts recognize that the best support is that which is most natural and most embedded within the social relationships of the individual with disabilities. As with the element of natural contexts, this has the added benefit of economic prudence.

*Before he moved to the Valley where we met him, Douglas lived and went to school in the city. He and his family were offered the “funny bus” (in the US we often call it the “short bus”) as part of the special education services. His mom, however, saw it as an opportunity to use the natural option – the city bus -- and politely declined the “funny bus.” Being an educator, she accompanied him on the bus through the transfer station to bus #9 and off at the school. After several days, she didn't stay on the second bus, but instead got in the car and drove to the school to make sure he made it off at the correct stop and went into the school instead of the much more interesting fire station next door. More days, more practice, even after the bus driver tried to assure Douglas' mom that all was well; he could do it! One day a woman who rode the same bus and made the same transfer offered to make sure Douglas made the transfer and got off at the school. Mom could release her support to this stranger who became Douglas' natural support.*

*All went well until the day there was an extra first bus on the line with a different driver. This driver did not stop at the transfer station because no one rang the bell and he didn't know that Douglas needed the #9. Since the bus didn't stop, Douglas simply stayed on the first bus and rode through the entire route. Of course, the school called mom. Vowing not to panic, she called the bus system and found out about the extra bus and new driver. When contacted, the driver reported Douglas was still on the bus and*

*made it to the transfer station on the second time around the route. Douglas got to school, albeit late. But more importantly his family learned that he had a good sense of where he was and where he was supposed to be. It has paid off throughout his adult life and means that he can safely be home alone – an option that offers not only more freedom for the family, but more autonomy for Douglas.*

Of course, natural support can take time to develop. Many members of the community have grown up not knowing much about disability and, because of the tradition of segregated services, sometimes not encountering people with disabilities. Even when they try to interact or be supportive, sometimes their efforts can fall short or simply be inappropriate because they have so little experience with people with disabilities. Some individuals with disabilities can be difficult to get to know or talk to, furthering the challenge for those who might provide natural supports. While natural support can take time to develop and nurture, the presence of people with disabilities in natural settings as described is an important precursor to the development of these supports. Over time, with more community participation and visibility of people with all manner of disabilities, more and more community members will feel comfortable and able to lend a hand when it is needed (see Figure 16-6).

The critical outcome measure is no longer whether someone receives “services” but rather whether someone’s quality of life improves. The emphasis is that the individual finds the support needed regardless of where that support originates. The neighbor who decides at the last minute to invite Ian to accompany him to a ball game or over for dinner is just as supportive—if not more so—of leisure activity as the official recreational therapist with a scheduled swim time each week, and should be recognized as such. The point—at least from our perspective—is not that all formal support services should be withdrawn or avoided but that they should be seen as only one source of the support that all of us need at one time or another.

**User Defined** An emphasis on informal supports and natural contexts leads logically to a third feature of the supported adulthood approach. The individual receiving the support is the only one who can define what is or is not supportive. Again, this directly challenges the controls of the bureaucratic structures to establish what “services” shall be available to an adult with a severe disability. Instead, the approach endorsed by all the examples of supported adulthood is to empower the individual to make such determinations. For example, a young man with aggressive behavior might use his behavioral repertoire to indicate a clear preference for spending his residential support dollars to maintain him in a duplex with one other roommate rather than the eight-person group home originally offered him.

In some situations, the “user” might be a whole family rather than any one individual. So, for example, parents might need to help define what type of service would be most supportive for a son or daughter or what balance of informal and formal supports would best match their own contributions to his or her lifestyle.

**Local Character** A fourth common feature in examples of supported adulthood is recognition that support should be community referenced. The emphasis here is not only that individuals should define what is and is not supportive but also that, once defined, that support should then take on the shape and texture of the local culture’s traditions, values, and opportunities. The most obvious level of community referencing is at the basic effort to “fit in.” For example, using a group home model as the exclusive type of residential service arrangement may foreclose the opportunities provided in many urban communities of apartment settings. Recreational opportunities should support and (if needed) provide training in locally valued activities (e.g., making a good ski run in Colorado, making a good pastrami on rye in New York City) instead of rigidly adhering to some standardized agenda that seems to imply, “All people with severe disabilities should learn to bowl.” Community referencing should draw on the traditions and values within a local culture. A tradition of resistance can also be supportive when identified as a valuable and important part of a local culture. What we are advocating by “local character” is not just nostalgia for some imagined era of the small-town simple life; tradition can include recognition of difference, even tension, which support for people with severe disabilities should not ignore in the pursuit of peaceful conformity.

*Ian lives in Oregon in a city with an active tradition of strong minority voices and social activism. Environmental issues alone offer any number of opportunities for citizenship and affiliation, depending on the side you choose to support. Ian already contributes his voice to at least some environmental debates in his use of canvas bags or his backpack when shopping. During a public employees’ strike a few years ago at the University of Oregon, Ian joined in support of his coworkers on picket lines. Ian may not have understood all the issues involved in the strike, but he was aware that the routines were different and that people he worked alongside were not at their posts. Joining the community expression of resistance, regardless of what he understood about the issues, not only allowed Ian to support his coworkers but also increased their willingness to contribute to his support in other ways.*

There is also a strong disability rights organization in our community. Although individuals with cognitive disabilities have not been well represented in the disability rights movement and while Ian is not yet a member of the

local group, he is assisted to contribute his support for disability issues. In the course of his job, Ian serves the university as a semiofficial “accessibility tester.” During one period, he began to consistently run into trouble with one of the automatic doors at the same campus building. The building was first on his morning route to deliver food supplies to cafés around campus. When he pressed the access panel to operate the door, nothing happened. Repeated calls by Ian’s coworker to the physical plant resulted in frustration on all sides for a while. Whenever the repair team tested the panel, it worked, but the very next morning it would not work for Ian. Eventually, careful sleuthing by his coworker and others resulted in the discovery that during routine maintenance at night, the emergency switch was being turned off. After this incident, Ian was occasionally asked to try out a new door or entry or ramp to test its effectiveness for someone with Ian’s type of wheelchair and skills. Our point is that supported adulthood requires attention not just to local traditions of peace, harmony, and patriotism but also to the minority voices and social activism that might afford rich and preferred opportunities for community participation and contribution.

**Universal Eligibility** Finally, a fifth feature of most of the emerging examples of supported adulthood—and perhaps the most controversial—is the principle of universal eligibility. Everyone who requires support to experience the full promise of adulthood should receive it. Unfortunately, since there are simply not enough formal resources for all who genuinely require them, only those who meet a more stringent test of poverty or extremity of need, whether temporary or chronic, receive services. In Moroney’s now classic analysis (1986), approaches that focus on a subgroup who are somehow “in most need” are described as reactive or residual. That is, such limited approaches perpetuate the problems of the welfare state programs that we summarized earlier. They tend to be stigmatizing, lack cost-effectiveness (because not preventative), and are destructive of personal independence and community membership (because of competition for services).

The customary rationale for this limited eligibility is inevitably tied to the professional client orientation to support services. If we break away from that constraint, however, then the universalizing of disability policy seems much more feasible (Bickenbach, 2001; McKnight, 1995; O’Brien & Murray, 1997). For example, if formal support services are the only officially recognized, legitimate responses to an identified social need, then competition for scarce resources seems inevitable. If informal supports are included and existing natural contexts are preferred, then the available resources for support are dramatically multiplied. The addition of informal support to the equation automatically increases the total of recognized resources. Equally important, formal support dollars become more cost

effective when used to encourage this informal sector rather than to pay the salaries of bureaucrats.

There is danger here as well, of course. The emphasis on informal supports can provide “cover” for those politicians and administrators who simply want to avoid the expense and challenge of meeting their responsibilities. The legal protections embedded in such landmark legislation as the Individuals with Disabilities Education Act and the Americans with Disabilities Act remain necessary for neglect of responsibility. Recognizing the value of informal supports should never become an excuse for not providing a social safety net for those who need it most.

## **DIMENSIONS OF ADULTHOOD REVISITED**

Given the elements of the reform of supported adulthood that seeks to reconceptualize services, we now want to return our attention to the three key dimensions of adulthood that we have discussed throughout this chapter. How might the elements of supported adulthood reveal themselves across the three dimensions of autonomy, membership, and change? We again use Ian’s experiences to personalize our discussion.

### **Supported Autonomy**

The years since graduation have been exciting and productive for Ian. He now enjoys many symbols of autonomy. Still, Ian will never be completely self-sufficient in many of the most important aspects of life. He will probably never be able to make independent and reliable decisions about some of the more fundamental areas of life: religious beliefs and abstract principles of moral behavior, long-term financial planning, or even when it is safe to cross a busy street corner. However, with appropriate support, he can attend church if he wants to (assuming it is accessible), reciprocate the kindness of friends and strangers, help manage a small bank account, and even negotiate some intersections. Self-sufficiency certainly entails a number of discrete skills and resources that Ian will never be able to develop or discover on his own. However, self-sufficiency also conveys a pattern of life that goes beyond individual tasks or skills. In this expanded sense, Ian’s autonomy is enhanced by appropriate types and levels of ongoing support.

*Work life is perhaps the single area that is most commonly associated with personal autonomy. For Ian, the promises of supported employment have been exciting and rewarding. He has a great job—and one that is uniquely suited to his skills and personality. Ian is a very outgoing kind of guy who likes to be out and about, driving his wheelchair and meeting people. The food services located in the university’s student union decentralized by putting small cafés in a number of the classroom buildings around campus. However, space is at a*

*premium, and the cafés can store only a small number of supplies. Ian’s wheelchair offered a legal vehicle that could convey supplies within the center of campus. With the assistance of vocational rehabilitation, a carrier was designed that fits on the back of his wheelchair for carrying these supplies, and he enjoys a regular route that takes him all over campus, meeting and greeting lots of different people. His job has changed over the years: adding tasks like collecting the receipts or breaking down cartons that once held supplies, adding new stops on the route, and increasing responsibilities for stocking at the main union.*

*Getting and maintaining this job has not always been easy. Some of the coworkers hired to support Ian have not been as successful as others. As supervisors and student employees change, Ian’s personal support agent—a person hired by Ian and his family as an advocate and intermediary with family, officials, and support providers (P. M. Ferguson et al., 1997)—has sometimes needed to help the new coworkers understand supported employment and its role in Ian’s life. Despite these continuing challenges, however, Ian enjoys his job and misses working when the university is on term break. We have seen his language and communication skills continue to grow and expand in the years since graduation and suspect that his daily encounters with new people have contributed. Ian illustrates just how important it is for the developmental disability service system to ensure appropriate levels and types of ongoing support to maintain him in his job. It is a commitment that should be more universally made and kept (Bellamy, Rhodes, Mank, & Albin, 1988; Kiernan & Schalock, 1989; Mank, 1996; Wehman & Kregel, 1995).*

*Ian also illustrates the contribution that effective high school transition services can make to successful adult experiences after school. Ian did not learn to deliver food in high school. However, what he did learn was what it meant to “have a job.” He did learn about making decisions. He did learn how much he enjoyed “going to work.” That is, the dimension of autonomy gained important concrete application for Ian as he sampled a variety of possible employment opportunities in high school and participated in other opportunities for making choices that mattered.*

*In March 1997, Ian moved into his own home. Several years later, he moved into a somewhat larger house in a different part of town, enjoying the new space, larger yard, and excitement of moving that this event offered. His housemates have changed as well in this time, but the couple who live with him now are about to celebrate their seventh year with him. With this stability has also come a regular routine. Weekdays always involve*

*a morning at work (unless the university is on break) with the remainder of the day punctuated by haircuts, a massage every few weeks, swimming to maintain range of motion and combat the gradual weight gain that seems endemic to middle age, and Wednesday nights with an old friend from high school. Weekends are the time for dinner parties with us (we get invited over often!) or other friends, short weekend camping trips to the coast or the hot springs, working on a large variety of art and craft projects—some of which become wonderful gifts for friends and family—as well as movies, a beer or coffee somewhere in town, or just a visit to the park to feed the ducks.*

*The year is punctuated with a round of parties and special events. The Easter egg hunt and Halloween haunted house draw larger and larger crowds from the neighborhood. The food is always good, the music and games are fun, and the atmosphere is celebratory. September brings some kind of theme party in honor of Ian's, his father's, and several other friends' birthdays—a Hawaiian luau has been one popular theme. Late summer usually involves a holiday—sometimes we all save up for something special like a trip to Reno or Las Vegas—but other times camping on the coast or the San Juan Islands of Seattle offers the needed respite from routine. Ian and his supporters are systematically exploring the accessibility of campgrounds in Oregon and Washington (Figure 16-7). But then there's always gardening to be done, canning and freezing of vegetables, painting the living room, fixing up the craft room, cleaning the wheelchair, making bread, picking up Dianne or Phil at the airport when they come back from trips—all the comfortable routine chores and tasks that have become a regular part of Ian's daily, weekly, monthly, and yearly life.*

Ian is benefiting from the increasing availability of “supported living” options within the service system. Simply put, supported living means that, despite Ian's limits, he should be able to live where he wants (in his own home), with whom he wants, for as long as he wants, with the ongoing support needed to make that happen (Howe et al., 1998; Taylor, Biklen, & Knoll, 1987; Taylor et al., 1991). For Ian, this support comes from Robin, his personal support agent, and Lyn, both his live-in companions; Charly, Shane, and Andy, who support him during some parts of his week; and Susan, the manager of the supported living program that manages his income from the service system along with other critical bureaucratic tasks. Ian receives several sources of income: the support dollars that come through mental health that pay his supporters, his earnings from his job along with Supplemental Security Income and Social Security Disability Insurance that pay for many of his personal needs and weekly expenses (food, some

rent, spending money, haircuts, personal stuff, massages, swimming, gas for his van), and contributions from his parents that help cover his mortgage and utilities as well as contributing to his vacations.

### **Supported Membership**

For us, as Ian's parents, it seems that the community is the safest place for him to be. The more hands that are there to catch him when he falls, the better. We firmly believe that the more deeply embedded Ian is in the life of his neighborhood, workplace, and the city in general, the more people there will be who will notice if he is not there and who will work to keep him there as a member of his community. Part of this involves some effort to allow Ian to fulfill his duties of citizenship. Ian has volunteered for several agencies or causes that he supports and enjoys. In addition to volunteering at the YMCA that we mentioned earlier, Ian has also delivered mail at a nearby long-term-care facility and helped a couple of times to put up posters around town advertising upcoming concerts for a local musical festival. It is important for Ian's membership in his community that he be given the support he needs so that he can, in turn, support his friends and neighbors.

Affiliations for pure fun and recreation are also important. The obvious term to capture the spirit of such activities is "supported recreation." Instead of separate, specialized, professionally defined recreational opportunities, the emphasis within progressive programs is now on the use of generic programs in the local community. Instead of Ian going to a special bowling night for all the people labeled mentally retarded in the whole county, the effort might be to let him choose what he wants to do for fun in the community and then arrange the supports and small groups necessary to allow those choices to be honored (Dattilo & Schleien, 1994; Germ & Schleien, 1997).

*We think of ourselves as part of Douglas' affiliations – one that is just for fun. Douglas can be quirky at times. One aspect of this is his commitment to things being in their proper place, orderly and organized. He, like some others, always eats the food on his plate in order at mealtimes and without mixing. First all the meat, then the vegetables, then the rice. We are not sure if he uses the same order each time, but he does complete one thing before moving on to the next. Of course, in Lenny's cousin's garage, this orderliness is a real asset and when Douglas leaves the garage is perfectly organized. And there is never a crooked picture on the wall in Douglas' house. All decorations on tables and shelves are precisely arranged and aligned.*



*This commitment to order can also lead to less happy results. We often bring small gifts to the family when we come each summer and some years ago we brought one of those decorative corks for wine bottles. It was made of a turned wood that is popular in Oregon. For Douglas, however, corks, once they are out of the bottle, are finished and meant to be thrown away – which was exactly what happened to our decorative cork. Ever since that incident we have enjoyed puzzling Douglas with gifts that challenge expectations and conventions. Mostly we have done this with vases. The family has a large cutting garden, so bringing vases seemed appropriate. One year we brought a vase that was plastic and collapsed flat. Douglas was puzzled, then intrigued. How could a plastic bag be anything but just that? Then another year we brought a ceramic vase that looked exactly like a brown paper bag. Again Douglas was incredulous and thwarted because he couldn't put it away with the paper bags, not to mention fold it flat. Then the round block of polished wood (with a small hole for a stem), and so on – each bringing Douglas into the joke and the ritual of gift giving and receiving while poking gentle fun at his compulsive commitment to order. Teasing Douglas most recently was the vase/planter shaped like a garden glove that has a hand in it, but doesn't. He opened it and laughed. I think he's in on the joke now.*

### **Supported Change**

Perhaps the central aspect here is to make sure Ian has the information and opportunity to expand the choices he has surrounding his autonomy and membership. Supported change should not involve a lifetime of programs, interventions, training, and habilitation plans. However, it should encourage a lifelong growth and development that will allow Ian to change his preferences as he learns new things. It should allow his relationships with people to evolve and develop without the frenzied impermanence of various paid staff who are here one month and gone the next. Ian should be supported in activities that will create new levels of independence but even more in activities that will create new breadth of experience. Finally, Ian should be helped to learn how to make his choices known in effective yet appropriate ways. Supported change should help Ian alter or minimize those behaviors that reduce his personal attractiveness to other members of his community (D. L. Ferguson, 1998).

*Many of these natural changes are occurring for Ian. His volunteer jobs have changed, as have his duties at his paid job. His first housemate, Faith, moved on to another phase of her own life, making it possible for Robin, who had worked for Ian some years previously, to come back into his life. New support people—Lyn, Alina,*

*Kareem, Jennifer, Shane, and Jessica—each of whom has spent several years in Ian’s life, have introduced him to new experiences and opportunities. Ian continues to learn. He is certainly talking more and about more things. His singing is better with the help of the Karioke machine he got for Christmas a couple years ago. He’s added swimming twice each week to stay fit and continues to take an active part in the planning and preparation for the many parties that happen at his house at every possible occasion. He has finally made it onto the Oregon beaches with the help of a beach wheelchair rented from Parks and Recreation. He will mark his 40<sup>th</sup> birthday with a trip to Las Vegas. While his life offers change and new opportunity, he also enjoys a comfortable and stable routine. It seems a good balance for everyone.*

Through all these changes, we learn more about how to engage Ian as an author in the adult life that is emerging. As we have watched Ian gradually separate his life from ours, our goal has not so much been one of self-determination in the particularly individual sense in which it is often applied to people with severe disabilities (Brown, Gothelf, Guess, & Lehr, 1998; P. M. Ferguson & Ferguson, 2001; Wehmeyer et al., 1998). Instead, we have sought with Ian a good life. We can support Ian’s autonomy, membership, and change. We can also support a growing self-sufficiency and completeness, but supporting self-determination has forced us to shift our thinking from Ian’s individual agency to our collective negotiations.

Philosophers have long talked about the importance of “agency” to our understanding of what it means to be an individual. What they mean by that term is our personal ability to act on the world around us, to be our own agents of change. The challenge of Ian and others with even more significant cognitive (and physical, and sensory, and medical) disabilities is how close they seem to come to the absence of agency in key parts of their lives. We do not really know what Ian realizes about himself, though we would dearly love to know. Perhaps we should not assume that Ian finds meaning similar to our own experiences of the characteristics of self-regulation, empowerment, and autonomy so often cited as central to self-determination. Certainly we are all interdependent, but the truth of the matter is that the balance of interdependence in Ian’s relationships is disproportionate in most matters as compared with our own. He is more dependent. He requires more care. He determines fewer things in the course of a day, week, or year than each of us do. Yet he does contribute in some very important ways to what occurs in his life. Does he choose? Sometimes and increasingly more so. But more often, he more indirectly influences people and events to end up being more okay than not okay from his point of view even when we do not know and perhaps cannot imagine what his

point of view is at the time. We want Ian to have a life that is more okay than not okay from his point of view most of the time.

One way we have found helpful to think of these issues is to borrow a couple of literary metaphors. Literary critics try to discover what a particular text means. Part of discovering the meaning of a text, or the “social text” of any person’s life, is finding out what the authors of that text intended it to mean—to gather and take into account all the possible meanings. That is never enough, however. The meaning of any text, including the social text of a life, belongs as well to the text itself and gets determined by each of us who “read” or participate in it. What even casual observers think about Ian’s life contributes to his story and influences the next chapters.

Like many conventional texts, social texts often have multiple authors. Ian and others with limited communication skills can contribute as coauthors to the text. Even if they do not noticeably interpret any particular experience for themselves, in any strong sense of human agency, by shaping the collective story in whatever way others can comprehend, the social text is enriched with their contribution for others to interpret and elaborate (P. M. Ferguson & Ferguson, 2001).

*This past Christmas, Ian made us bulletin boards—decorated around the edge with buttons and charms and pieces of old clocks. He gets help to pick the colors and textures, and he helps with most of the gluing. In past years, he also made raspberry jam, marinated mushrooms, canned pears, and applesauce. He has also made refrigerator magnets, tree ornaments, and hand-painted mugs and plates. Over the years, he has gone shopping for socks, tea, coffee, really good chocolates, jewelry, winter scarves, and decorative candles. The results of his holiday efforts are certainly shaped by those that support his participation in the season. This is a part of the complexity of Ian’s adulthood that we have come to understand. His taste and choices always reflect the people in his life. Our Christmas gifts come as much from them as from Ian. For our part, we have come to love the variety and choice that go into the content of Ian’s gifts. Of course, we also cherish the self-satisfied smile that he always has when he hands us the present as something that is uniquely Ian’s.*

*Christmas is beginning to have a comfortable annual routine. The first holiday we went to Ian’s house seemed odd, much like it must for all parents and their adult sons and daughters. Ian comes to our house now for Christmas Eve, Christmas morning, and sometimes Christmas dinner. Then we go to his house for dessert and more gift opening and good company with Robin and Lyn and some of their family and friends. The routine*

*varies somewhat, but it is a routine that we all enjoy and anticipate—and it is one we have all created together.*

## **Multidimensional Adulthood**

For us the final key to understanding the full meaning of supported adulthood—indeed, of adulthood itself—is to recognize that it has no one single meaning. Autonomy is a very important dimension of adulthood, but there are others. Unfortunately, most attempts to describe the promise of adulthood for people with severe disabilities have tried to accomplish it by making careful discriminations in the meaning of autonomy and independence so as to account for the genuine limits in self-sufficiency that severe disability might actually impose (this seems especially true of severe cognitive disability).

We believe that a multidimensional approach to adulthood allows a clearer way of interpreting the situation. Instead of trying to subsume everything that we want to include under the single rubric of independence, a multidimensional approach allows us to thicken our description of adulthood with the additional—but coequal—strands of membership and change that lead to the more accurate notion of adult “interdependence.”

As we have described earlier, Ian’s cognitive limitations and multiple disabilities are significant enough that the strand of autonomy in his version of adulthood may not be as strongly visible as his strand of membership. The strand of personal change and growth may allow the balance between the other two strands to change over his lifetime. It seems to us that a full understanding of adulthood in our society would allow us to avoid dilemmas of linear, one-dimensional thinking where degrees of “adulthood” occur on a single line of autonomy and independence. Adding other dimensions is not an excuse for limiting Ian’s independence; it is an interpretation that expands his adulthood. Ian’s adulthood is an expression of the relationships he has with his parents, his paid supporters, his friends, and his neighbors that contribute to defining what happens to him day to day. To truly support his adulthood, we are striving for relationships that nourish rather than smother, relationships that flourish rather than atrophy, and relationships that author rich stories of lives lived rather than reports of outcomes achieved.

## **Some Dangers Ahead**

**A Cautionary Conclusion About Unkept Promises** Supported adulthood seems to provide an important summary of how social services might accomplish a practical merger of personal independence and community support. However, claims of relevance and value for such ideas should always be chastened by the history of social reform efforts

in our country. Too often our reform optimism has been followed by decades of unintended consequences that seem all too predictable in retrospect.

There is a definite danger that arguments in favor of the supported adulthood approach could overemphasize the cost-effectiveness of such elements as the use of natural contexts and the encouragement of informal supports. Some economic savings may, indeed, be available through natural contexts and natural supports. However, as experience with the deinstitutionalization movement has shown, effective community support can suffer if justified primarily on the basis of financial savings. The arguments for adopting supported adulthood logic must be careful not to imply any enthusiasm for underfunded social programs. The economic justification for the approach is that it rationalizes spending by tying it directly to valued outcomes, not that it saves money.

A second danger with supported adulthood is to justify unintentionally an even greater reliance on a charity model of social support. One of the risks in calling for procedures such as increased reliance on community-based responses that encourage informal supports is the creation of a one-sided, libertarian abandonment of legitimate government responsibility to ensure the health and welfare of its citizens with disabilities. Of course, this move to the privatization of welfare gained popularity during the Reagan administration and seems to be enjoying continuing appeal. The problem is that the charity model almost unavoidably accepts the systemic inequities that occasion the need for charity in the first place. An effective disability policy must challenge inequity and discrimination in our society with distributive and protective systems within the formal structure of social agencies. Supported adulthood should illuminate a comprehensive, egalitarian approach to a national disability policy, not just look for volunteers to step up in an age of social divisions resulting from our class structure and continuing racial, gender, cultural, and religious discrimination.

A final danger in the approach is closely related to the potential overemphasis on charity. Just as the rediscovery of informal supports and natural contexts can be exaggerated into a privatized social policy of volunteers and cheerful givers, so can the concomitant deemphasis on traditional versions of formal supports lead to an overblown anti-professionalism. Certainly, those within the field of disability services must recognize the value of properly focused expertise and technology in improving the quality of some people's lives. The contention that excessive professionalism has often encouraged a dependency role for disabled people should not entail the abandonment of all the wonderful advances made in the behavioral and life sciences.

Despite these very real dangers of misapplication or distortion, the value of moving rapidly toward a vision of supported adulthood is worth the risk. To us it seems to represent the only hope that Ian's "flight" into full adulthood will be a smooth one. There are thousands of Ians "taking off" every year in our society. There are thousands more making their way as adulthood moves from "young" adulthood to middle age and beyond. We have made implicit promises to all of them for as full and rewarding a lifetime as they can achieve. The true risk is the human cost of not doing everything we can to fulfill those promises.

## **Suggested Activities**

Think about and discuss with your colleagues the ways in which you do and do not operate as an "adult" in terms of (a) self-sufficiency and (b) autonomy.

1. Think about and discuss with your colleagues all the things, events, and supports you obtain from your own parents or other family members.
2. Inventory services available for an individual with severe disabilities in your community. Try to identify the following things about each agency or group providing services:
  - a. Mission and philosophy of those providing the service
  - b. Role of the family in program design, monitoring, and improvement
  - c. Role of the adult in program design, monitoring, and improvement
3. Visit a residential or vocational program in your community that provides services for individuals with severe intellectual disabilities. Try to listen and notice things that reveal the ways in which the people served and supported by the program or service think of themselves as adults and are thought of by others as adults.
4. Talk with someone who works directly with individuals with severe disabilities (e.g., in a vocational support agency or a residential program). Find out how he or she views adulthood for the people they try to support.
5. Talk with a parent or a sibling of an adult with severe disabilities about his or her perspectives on how best to support the family member with the disability.

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**FIGURE 16-1**

Ian at his High School Graduation Ceremony

**FIGURE 16-2**

Ian Often Meets Friends at One of the Local Pubs

**FIGURE 16-3**

A favorite Activity is Hitting the Slot Machines at a Nearby Casino

**FIGURE 16-4**

Ian's House and Front Yard

**FIGURE 16-5**

Ian at Work with Cart

**FIGURE 16-6**

Ian with Coworker

**FIGURE 16-7**

Ian and Lyn Enjoy Camping Trips to a Nearby Lake