

**WHAT IS LIFELONG LIVING AND HOW  
DOES IT RELATE TO QUALITY OF LIFE?**

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RUNNING HEAD: Lifelong Living

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### Abstract

Lifelong living addresses the challenges that persons who have experienced a traumatic brain injury face after formal rehabilitation ends and it is time to adjust to long-term daily living. Each lifelong living program is personal and unique, according to the abilities and resources of the specific individual. Consumer control of programs, within individual abilities, helps to assure personal responsibility and self-determination.

Residential placement is not synonymous with lifelong living. Many of the supports required in lifelong living can be developed from existing community services with specialized programs used as necessary. Because of the long term nature of most programs, funding can be a formidable challenge and a number of approaches are being investigated to moderate direct costs. The ultimate success of lifelong living programming is measured by the lack of institutionalization that it "suffers" over time and how such programming helps the individual improve the control and quality of their life.

## **WHAT IS LIFELONG LIVING AND HOW DOES IT RELATE TO QUALITY OF LIFE?**

The end of formal rehabilitation services may be a convenient point to consider the start of lifelong living programming for a person who has experienced a traumatic head injury. The formal concept of lifelong living itself, is relatively new to this field. It represents another point on the continuum of resources for some people who have experienced a traumatic head injury<sup>1,2</sup>. By virtue of our ability to begin to recognize this issue, it may be considered as an advance in our field as we learn more about both the power and limitations of our technology.

On the other hand, any assumption that living begins after formal rehabilitation ends is a poignant reminder of many miles left in the maturation of our service delivery system. It is an elementary fact that a traumatic head injury often changes the life of the individual and those around them<sup>3</sup>. However, life is not placed on "hold" immediately following the injury or during formal rehabilitation. Still, it is ironic how often we make this type of demand during the "rehabilitation process" on the person who experienced the brain injury and their support network. Thus, in our attempts to assist in the improvement of the quality, self-direction and dignity of life for a person who has experienced a traumatic brain injury, through lifelong living programming, we must be careful to avoid its institutionalization.

### What is Lifelong Living?

Lifelong living addresses the challenges that persons who have experienced a traumatic brain injury face after formal rehabilitation has ended, a stable discharge environment has been established and it is "time to get on with living." It is a time when a person is again recognized for their overall make-up and character, rather than for one catastrophic event; when the "brain injured patient" is replaced by the "person who experienced a brain injury." While we may continue to acknowledge the significant residuals that may remain after the accident, we also begin to recognize the individual as a "whole," albeit different person again. A brain injury changes a life, but over the long term it must not define the life.

For some people, lifelong living means returning to full or close approximations of life as it existed before to their brain injury. For some, it means near total dependency on others for daily needs. For a large majority of those who experience traumatic brain injuries, it means something in between; of being capable of meeting some personal needs, but needing various levels of assistance in other areas.

For all persons who have experienced a traumatic head injury and their support systems, lifelong living programming signifies a shift in principal effort and attention from attempts at aggressive restoration of lost ability to adjustment to the challenges faced in daily life, as much as possible, within one's abilities. This shift does not withdraw the hope and effort directed towards continued gains, but places a different emphasis on how resources are managed. More effort is directed towards maximizing the benefits of one's presenting lifestyle than towards attempts at aggressive development of abilities to promote a different lifestyle. This is not to deny the potential for continued recovery, but to recognize existing potential when the rate of recovery slows.

The need for lifelong living assistance must not denigrate the person involved. By definition, no one in a society is totally independent, we all require assistance from others and have our own individual lifelong living programs. Depending how we individually approach life, our personal lifelong living programs may be a spurious combination of daily interests and obligations or a

systematic plan that carefully accounts for family, work, interests and other factors. Most importantly, each person is assumed in control of their plan and responsible for their destiny in terms of making conscious choices, accepting consequences for decisions and finding the resources required for daily living.

Unfortunately, it is too easy to assume any number of treatment models when addressing long term issues among persons with disabilities. These models may be highly effective during the initial stages of intervention, when the individual and their family are highly dependent upon others for almost every need and lack the knowledge or skills required to address presenting issues. However, the "price" for this assistance on a continuous basis can be high. It often includes temporary loss of self, lack of participation in the decision making that affects personal destiny, and being viewed for one's deficits rather than abilities. Over the long term, this is detrimental to personal destiny.

In society, few people survive on their weaknesses. It is what one can contribute to others that is important. The assistance that one may need from other people is balanced by what they can give to others, or how they, by their own choice, use that assistance. Apportioning this responsibility to someone else increases the chances of a lower quality of life for the person in question.

Obviously, a significant number of persons who have experienced a traumatic head injury require some level of support in managing daily and long term personal affairs. The challenge is in finding a mixture that leaves the individual in the greatest level of personal control that they can responsibly administer. Providing too much assistance can foster dependency, resentment and can be counter productive to personal determination and sufficiency. On the other hand, too little assistance may set the individual up for failure and regression from previously acquired gains.

### Beyond Empowerment

Lifelong living models must celebrate each individual for their abilities and contributions, not their deficits. In an effective model, each person is responsible for their choices and destiny. This ideal is tempered by the realities that not all people can independently manage their own lifelong programs; an obvious qualification for many of those seeking assistance. There is frequent concern for dependent persons who have experienced a traumatic head injury, relative to each person's cognitive and behavioral disabilities. Each person's unique challenges present questions about what type or how much support is appropriate to the situation and where this assistance will come from<sup>4</sup>.

The use of advocates, ranging from family members, to professional case managers, to court appointed conservators presents one way to address this responsibility<sup>5</sup>. Although this may be effective for persons with severe impairments, friction frequently occurs in cases of less severe impairment, or when services are simply not available. These types of supports, when improperly applied also bring about the classic charges of overprotection by the advocate on the one hand and concern about lack of insight by the person who has experienced a traumatic head injury on the other hand. In addition, the demands involved in assuming responsibility for the life of another individual frequently becomes overwhelming for any advocate, affecting the quality or duration of their involvement<sup>6</sup>.

Empowerment training has received increasing attention as a promising alternative in promoting lifelong needs. Persons participating in such training learn how to take greater control of their lives along with the responsibilities for such actions. The orientation of this approach is appealing by virtue of the greater control it should give one over their destiny. The effectiveness of this approach

has not yet been fully evaluated. It is likely to offer promise for many persons with mild to moderate impairments, but must be evaluated on a case by case basis.

Although empowerment may be viewed as a positive step over advocate oriented systems, it still relies on one group of people giving "permission" to other people seeking to re-gain control of their lives and destinies. In daily living, responsibility for one's life is an implicit assumption. For most people, assistance and restrictions in decisions of daily living and destiny are added, rather than the converse of challenging the individual to demonstrate independence from an assumption of full dependence.

To some this may be a subtle distinction; but it is important for a number of reasons. First, it focuses on abilities rather than disabilities and the assumption of capacity over incapacity. Second, it places the individual in control of their life and destiny, within their capacities, and makes this a key cornerstone of any programming, rather than an afterthought. Third, it clearly places the individual in the role of the consumer and programming in the role of a service that the consumer may select. Thus the individual directs the program, rather, as happens in so many situations, the program directs the client. Fourth, there is constitutional precedent for this distinction. In our society, one is innocent until proven guilty, is assumed to be in control of one's faculties until proven otherwise, etc. In other words, we assume the strength and power of the individual until demonstrated otherwise and then it is only through extensive procedures and documentation that self determination may be challenged.

Although the individual may choose to or need to resign these basic rights of self determination during early phases of treatment following a catastrophic injury, this is often a temporary condition. It must be rescinded as quickly as possible, if the person is to reassume the power over their life that they are capable of, responsible for and entitled to once this brief period of treatment has ended. For many people a broad range of supports from informal assistance to full conservatorship may still be needed according to the level of disability that a person demonstrates following a traumatic head injury. However, these supports must be added through demonstration of need, rather than "heaped on" through assumption of deficit.

### Where Does Lifelong Living Programming Occur?

Residential setting is only one option in lifelong living programming. Most people return to non-formalized living settings post injury, typically with a family member or alone in the community<sup>7</sup>. Except for programs serving the catastrophically disabled (e.g., persistent vegetative state), few formalized programs are capable of providing for all lifelong living needs. It is also unlikely that such comprehensive programs would be desirable. Social, vocational, financial and other major life issues, that affect the daily life of each person, are just as important as habitat<sup>8</sup>. Providing needed services outside of the natural fabric of the social environment, where these activities usually occur, would be to deny opportunities for normalization and personal destiny.

Programming must begin within a normalized environmental focus, with supports, added as needed to help each individual maximize the quality of their life, as any other member of society. Hence, the community is the obvious place to begin considering programming functions<sup>9-11</sup>. Schools, jobs, recreation centers, counseling programs and other community services may be the first line of inquiry and involvement for those with minimal impairment.

Obviously, some people may need levels of support that are beyond local resources. More specialized programs may then be appropriate. Non-community based programming is also a

viable option, when it best serves the needs of the individual. Thus, the sheltered workshop which is the bane of one individual, may be the aspiration of someone else with other interests, resources and challenges. Balances between personal aspirations and viable options, are realistic challenges that must be faced on a daily basis in every person's life, whether they or someone else directs their lifelong living program. When someone besides the individual in question takes this responsibility, however, there is greater pressure to assure that the best interests of the dependent person are being addressed.

Finally, programming must be dynamic and respond to the ever changing needs of the individual and their environment. This includes variables such as ageing, personality, community development, family changes, financial issues, physical changes, medical events, etc. The complex inter-relationships of these variables can make it difficult to predict the future. However, it is possible, and critical to develop a strategy to address life needs over time.

### Beyond Therapy

The rejection of a therapeutic model as the basis for lifelong living programming does not refute the importance of therapeutic intervention within daily living. Obviously, persons who continue to experience disabilities are likely to benefit from appropriate therapeutic intervention. In addition, just like any other member of the community, new problems or challenges may arise that require the assistance of others, including professional services. Prospective assistance may also be sought to develop new skills, enhance self awareness and aid personal growth. Again, a variety of options may be open to the individual to address these interests, including therapeutic intervention and formal education. The benefit of educational systems may lie in their cost, opportunities for mainstream socialization, and self esteem that they provide. Regardless of the type of intervention utilized, it is preferable to focus on new skill development rather than the amelioration of existing deficits.

At a minimum, this distinction focuses on future ability instead of past loss. While some may feel the distinction is splitting hairs, it is never less important. It helps to focus on the fact that in a lifelong living program, therapeutic services are used by the individual to enhance their abilities and quality of life. In essence, services are directed by the consumer towards personally directed goals rather than directing the goals of the consumer.

### Rights and Responsibilities

Someone (most frequently the individual themselves) must assume the implicit responsibilities for each living person. Although the residual sequela following a traumatic brain injury may require a different role for the individual post trauma, each person (or their conservator) still retains the same social responsibilities of all members of society. Accordingly, each individual has the right of self determination as well as the responsibility for the choices they make. Each person has the right to secure or defer services and treatment as well as the obligation to find the resources to cover accrued expenses. Refusal or unavailability of these services or treatment may not be sufficient cause for deferral of personal responsibility. Each person has the right to be viewed for their abilities rather than their deficits. However, this right comes from the active demonstration of such skills rather than via the expectation of respect for "potential."

Exercising these rights requires personal responsibility, advocacy and coordination of effort among individuals. In a society where opportunities are abundant, but rewards are the product of

effort, individual persistence and social competence are critical in determining quality of life. Hence, returning and remaining in the community are often two different issues. The resources and ability of the person with a traumatic brain injury to achieve each of these goals must be individually considered.

For those who are not capable of self-determination or community tenure, there is still the question of who is ultimately responsible. Family members have traditionally assumed responsibility for many dependent persons. However, the life span of the family unit is generally shorter than that of the dependent person. Parents die, spouses separate, siblings and children grow apart, resources are inadequate to meet presenting needs, or personal interests change. Determining what level of responsibility society maintains for this individual remain unanswered<sup>4</sup>, with services being provided on a take what you can get approach. This frequently results in a substandard level of living in which the individual is more aptly considered a survivor; a person who is literally hanging onto the fringes of society, instead of a contributor. It also makes prospective long term planning difficult.

Turning to public resources does not guarantee cost-effective or qualitative programming. Each person in our society has a right to access public services regardless of handicap. However, entitlement and access are often two separate issues. Public funds can be scarce and subject to political winds. A myriad of regulations designed with the intent of safeguarding the individual often work towards the detriment of the person. A number of programs are skeletons of their original intent. This is frequently caused by program mandates that are beyond their level of funding, requiring cuts and compromises in services. The issue is not the goals of such programs, but their ability to carry out their objectives. Legal and legislative remedies to take time. When such challenges are successful, they are often at the expense of other programs.

Obviously many public programs do work. Similarly, private, non-profit and proprietary programs present their own challenges and levels of success. While it can be generally assumed that one cannot get something for nothing, the provision of money is no guarantee of quality. Each program or service must be judged on its operational merits and not on theory or assumptions. Lifelong living programs are complex and multi-faceted, requiring a blend of resources, priorities and opportunities.

Ultimate solutions to these challenges are not available, which in fact may indicate how "normalized" lifelong living programming presently is. Few people in life have crystal balls or guaranteed futures. This does not, however, absolve our responsibility to seek better answers or neglect those who are dependent or in need. The question remains how.

### Summary

In summary, lifelong living programming signifies the transition from a primary focus on aggressive restorative therapy to adjusting to the challenges faced in daily life, as much as possible, within one's abilities. This shift does not withdraw the hope and effort directed towards continued gains, but places a different emphasis on how resources are managed. The long term abilities, challenges and resources that each person presents requires an individualized approach to long term planning. In many cases, prospective planning may not be possible. In all cases, each individual must regain the highest levels of control and self-determination possible. This will vary from complete control and self-determination to complete dependency, as in the case of persistent vegetative state.

The challenge is to break the therapeutic mold that drives most program delivery systems and fosters dependency. It is incumbent that lifelong living programming recognize the person for their strengths and provide support for demonstrated, rather than assumed weaknesses. Many persons who require formal planning for lifelong living will need support and perhaps significant daily intervention. However, the selection of such services should be consumer driven. Normalized and community based services are often the first choice, with specialized also a viable option in individual circumstances.

The costs for lifelong living services will vary with individual need; from negligible to staggering. However direct service costs are not the only variable to be included in the equation. Not having access to services also carry costs in the form of emergency medical, legal and housing costs; indirect costs to caregivers; community costs from lost productivity, etc. Gains made during aggressive rehabilitation treatment are also at risk without proper support. This includes costs for re-treatment following decompensation as well as the lost value of the substantial investment already made for initial treatment and rehabilitation services. Unfortunately, many of these costs are hidden or considered secondary, and rarely make it into benefit-cost analyses.

Financial considerations aside, there is also the personal demoralization that can occur when one begins to regress or presents little social contribution. In our society it is important to feel needed and to know that someone else can depend on you. This need can be further frustrated when potential supports exist, but are individually not available. The sense of helplessness and lack of self worth are readily apparent when one is a social burden rather than a social contributor.

Many of the supports required in lifelong living can be inexpensive<sup>12</sup> and consume no more resources than most people require in daily social function. Unfortunately, our impression of lifelong living programs often encompasses massive, institutionalized and treatment oriented programs.

Who will care for dependent persons who have experienced a head injury and cannot assume this responsibility remains a major question. Few people have the interest, energy or resources. Funding lifelong living programs is also a formidable challenge. One cannot look exclusively to public or private support. Models that blend funds from a variety of sources may offer the best approach, but are still novel rather than common.

The success of lifelong living programming will best be measured by the lack of institutionalization that it "suffers" over time. The key to successful programming is to recognize each person as a whole and not by a single catastrophic event. At some point in life, each person must transition from a brain injured patient to a person who experienced a brain injury. Good lifelong living programs are dynamic but not obtrusive. They exist to assist people in the self-determination of their lives and must blend in with individual lifestyle. Thus, the success of any program will be measured not only by how much it helps the individual improve the quality of their life, but in its transparency in facilitating this goal.

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