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Independent Living and Social Inclusion

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Abstract

After a few years of opportunities for independent living actually materializing for individuals with intellectual disabilities, the present situation may be analyzed to gauge the social access and community participation enjoyed by this group, as well as. Moreover, new prospects can now arise to serve as a focus for the individuals themselves, their families, their communities, professionals, organizations, and government bodies.

Keywords: Independent living. Quality of life. Social inclusion.

The independent living support service "I'm going home" gives backing to people with intellectual disabilities (ID) as they embark upon an independent life in their own home and in charge of their everyday living, by providing intermittent support and planning. Although its clients can enjoy full independence, they also need follow-up, help with planning, learning, guidance, support or mediation at certain times and with certain activities in their day-to-day life.

The aid that these people receive for autonomous living is provided through structured Personal Care Plans (PCP) which cover issues such as:

– Taking care of oneself: health, diet, hygiene and so forth;
– Running a home: cleaning, washing, household finances, and home maintenance and upkeep
– Social access and participation: interpersonal relationships, use of community resources, consumer habits, etc.

These areas largely determine the type and function of the support given to the person in their independence. However, it would be pointless to make plans for care without a future outlook that goes beyond needs and also considers goals, expectations and hopes. This is one of the main assets of this service and what really sets it apart from others – an emphasis on each individual's quality of life, as rendered through better results in:

- Independence
- Social relationships
- Contributions
- Community participation
- Personal well-being

It is important to note here that agreeing on personal capabilities and structuring supports is relatively straightforward in the concrete domains of self-care and home management, whereas this is not always true of social access and participation, where some of the most salient obstacles to desirable results arise.

The ecological perspective on the workings of people with ID suggests that meeting needs and desires pertaining to oneself and one's immediate surroundings tends to present independence-enabling forces,, whereas broadening the context to take on interdependence with other people and settings raises the specter of the great unsolved problem of independent living: social inclusion. Why is this?

For Dr. Robert Schalock, quality of life is a concept that reflects an individual's desired living conditions in eight core dimensions which are interrelated and underpin the working goals for supporting independent living. These dimensions are:

– Emotional well-being
– Interpersonal relationships
– Material well-being
– Personal development

- Physical well-being
- Self-determination
- Social inclusion
- Rights

He goes on to define social inclusion as the sum of the individual's experiences and opportunities to participate in the school, community, workplace, home and leisure, all of which should be the same as for someone of a similar age and culture without a disability. These opportunities can be gauged using a set of very specific indicators that allow us both to analyze the objective conditions for interacting with a social context, and to ascertain the person's subjective perception of these. The indicators measure acceptance, status, support, the work environment, community integration and participation, roles, voluntary activities, and the living environment. Broadly speaking, the indicators describe three major areas:

- The person's presence and participation in the community
- The quantity and quality of available social networks
- The community roles that the person performs

Underscoring the importance of and need to prioritize on normal living conditions, Schalock concludes that the community constitutes the absolute context for quality of life. This points to the existence of universal lifestyle standards and has clear, far-reaching implications for the challenges and resolutions that all professionals and services set when defining their work with people with a disability.

So, to what extent can a person with ID living independently achieve social inclusion? Naturally, we are referring here to people who live in ordinary settings comprising their own home, neighborhood, and town. This physical location is not only the basic building block for the person's future ambitions but also affords multifarious opportunities for them using and enjoying the many local amenities: going to the doctor's, going shopping, attending neighborhood meetings, and going to the bank or running an errand. All of these experiences offer some insight on the extent to which someone is part of a community.

From the very outset of a person's independent living plan, the "I'm Going Home" service attaches special importance to his/her social networks with what it calls the *Circle of Trust* (Figure 1). The aim of this 'tool' is to organize and extend the significant relationships that the person has, distinguishing between:

- Formal support: provided by the staff and services who care for the person (both ordinary and specific), and
- Informal support: the individual's natural social network – family, friends, partner, neighbors and acquaintances.

A review of the makeup of our clients' *Circles of Trust* reveals that most include numerous professionals who, in keeping with the culture of cross-disciplinary work, endeavor to liaise with each other in order to provide balanced, coherent care. However, when this involves both specialist disability services and mainstream services, the values and objectives of possible interventions sometimes clash. For the time being, when this occurs the specialist services must take on the roles of mediator and facilitator in order to increase receptivity among the general social service network.

Analysis of the informal support that our clients have has shown that this differs hugely from person to person. Although almost all can count on their family members

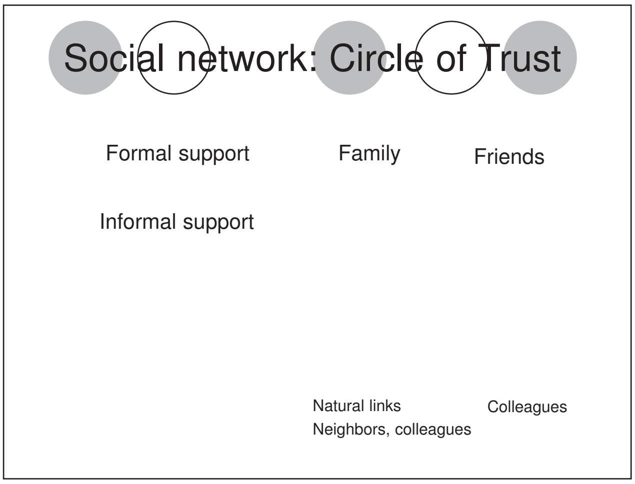

Figure 1. Social network: the Circle of Trust

and legal representatives, there is considerably less real involvement from others. The individual may know and interact with various people in an array of settings, but these relationships rarely develop beyond the original context. For instance, the person may be on good terms with their colleagues but never see them at weekends, or have neighbors who will lend them a hand if necessary but seldom ask them in for coffee. We must therefore ask ourselves how we can make social settings more permeable to people or collectives who for one reason or another are excluded from naturally occurring relationships and participation. It is also important to note that there are significant differences between the *Circles* of the people who wanted and planned for independence and those who had it thrust upon them.

Finally, on the roles and social status of people with ID who lead independent lives, for me the most significant finding of our analysis is the ambiguity and contradiction that surrounds them in terms of other people's perceptions. Is it not paradoxical that when someone chooses to take charge of their life others should see them as 'unfit' or 'unlikely' to enjoy and make a go of it? Indeed, is it not a fact that many of us still struggle to envisage such people living in their own homes? To my mind the answers to these two questions are clear proof of our mindset vis-à-vis the social position of individuals with disabilities.

Another dimension to consider is whether this belief holds true for various age groups. Our independent living support service caters for people aged between 18 and 65 (Figure 2). Such a broad spectrum should encompass three major stages in life: youth, adulthood and senior citizenship. Theoretically, these three subgroups could be used to determine very distinct personal situations, needs and expectations. However, this is not the case at all. For most people there is only one long stage during which, regardless of the person's age in years, their ability to live independently is continuously undermined. As a result, their transition to adulthood is either dragged out or put off indefinitely, thereby restricting or preventing them from achieving a normal role and status. This goes on so long that the person's physical and mental health eventually begins to deteriorate and we classify them as elderly, at which point they are put back on the path towards progressive and future dependence.

Our readiness to curtail people's independence or strip them of it altogether never ceases to amaze me. I firmly believe that we must continue working towards differentiating between each stage of life, calling for specific age-based rights and duties.

The average age of the people cared for on this service is 41.5 years. According to studies on the ageing of individuals with ID, signs of deterioration can start to become manifest at around 40. Because most of our clients are right at this critical stage, this has been linked to some of the setbacks and repercussions that we have observed in their well-being. In the seven years that the "I'm Going Home" service has been in operation, we have seen some individuals suffer a slow onset of age-related conditions such as diabetes, high cholesterol, cardiovascular events, shortness of breath, injuries from falls, loss of memory or confusion, cataracts, and others. All of these changes to mental and physical health require various adjustments to both the person's living arrangements and their planned support and follow-up:

– After one-off or short-lived episodes, the client has gone back to living as before and continues as normal. A record is made of the event in their follow-up process as a possible first warning sign.

– With episodes that are longer lasting or have more of a bearing on the person's life or ability to look after themselves, the individual is usually the first to want to determine how and where their needs will be met. This can entail stepping up the support provided, arranging home help services, or moving into residential care for the elderly.

Some of the people we care for have also resorted to the general network of social services aimed at the elderly, with varying degrees of satisfaction. What is striking about this type of situation is that although these

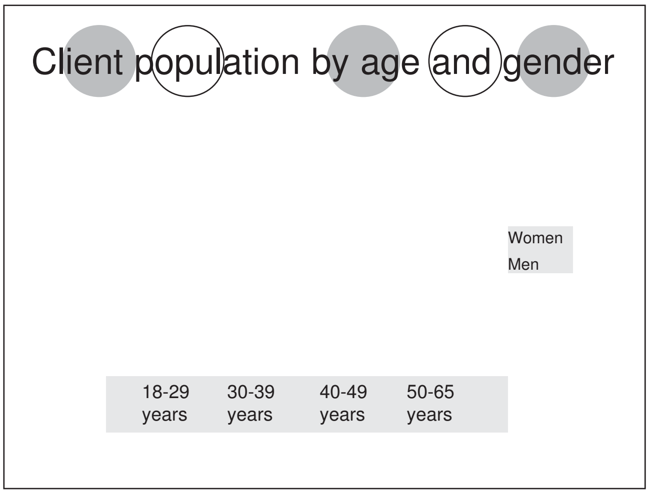

Figure 2. Client population by age and gender.

two segments of the community share common needs, the focus is on what sets them apart: on disability, rather than old age. The general increase in life expectancy in recent years, which also holds true for people with ID, has given rise to a new issue: old age with ID and the subsequent need to question existing care models for this time of life. Some believe that specialist services should be set up, whereas others argue that the criteria and resources applied here should be the same as for the population at large.

Some of the situations described have highlighted the extent to which the support provided and referrals made are in line with 'normal' criteria, sometimes to the point of blatant discrimination. These include refusing or challenging the need to carry out medical tests in cases of suspected neurological deterioration, on the grounds that the person already had brain damage before the warning sign was apparent. Another instance is the dilemma of whether a home for the elderly is more appropriate than one for the disabled, when an individual requires temporary or permanent residential care. Once again, it all boils down to deciding between inclusive or exclusive criteria when seeking contextual responses to individual and collective needs and desires.

Concepts and theories aside, our work on the ground is proving day after day that:

– An array of resources and models suitable for differing personal profiles is needed.

– We cannot make decisions based on needs and difficulties alone; major importance must also be attached to personal choices and expectations.

– The person concerned must be at the heart of all service planning.

– Opportunities and decisions are, again, contingent upon personal background and the extent to which the person has previously achieved social inclusion.

– Programs and models for cooperation and coordination must be set up as part of the social services network.

– Specialist care services for people with disabilities can shore up the network of general social services to adapt it to specific needs.

– It is incumbent on the authorities to devise cross-cutting policies and universal services rather than taking a piecemeal approach based solely on creating more specialist services.

Spain's recent approval and publication of a law to promote personal autonomy and dependence and, even more significantly, the Regional Government of Catalonia's Social Services Act of 11 October 2007 should set a new reference framework for drafting social policies in our country and pushing forward new programs, project and services that will ultimately shake up and improve the current state of affairs. Let us hope that the coming into force of these laws will uphold and bolster their underlying principles and objectives.

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News

Ms Montserrat Trueta i Llacuna, the President of the Board of Trustees of the Fundació Catalana Síndrome de Down, has been awarded the Gold Cross of the Civil Order of Social Solidarity by Spain's Ministry of Labor and Social Affairs.

Pursuant to Order TAS/3126/2007 of 22 October 2007, this honor has been awarded to Montserrat Trueta at the behest of the State Secretary's Office for Social Services, Families and Disability, in recognition of a lifetime's contribution to providing care and advocacy for people with intellectual disabilities, and of her work at the head of the Fundació Catalana Síndrome de Down.