Abstract

Background
It is critical to improve Quality-of-Life since it has impact on the future life of the young people with disabilities. Many youth with disabilities have difficulty in successfully making the transition from school to adult life. In addition, there is evidence that students with disabilities receiving special education services in public schools score lower than their nondisabled peers on Quality-of-Life factors such as life satisfaction, self-determination, social belonging, and empowerment.

Aims
This study used interactive focus groups to examine the perspectives of Portuguese youth with disabilities who are institutionalized, about their life-satisfaction and personal capacities and its relationship with their actual expectations and future plans. Additionally, we heard from the youth about their past experiences in school related to transition to adult life preparation including perceived barriers that had an influence in their current life.

Methods
Four participants with physical disabilities were interviewed in one focus group.

Results and Conclusions
Through the analysis of audio-taped interviews, several factors were identified for these youths as having a great influence in their actual situation of life and future plans. Barriers and facilitators to transition were identified which included: personal development, community opportunities, social environment, school experience, assistive technology. The results of the study will discuss promising practices in transition practices that are needed in order students with disabilities have success in transition to adult life.

Keywords: Youth with disabilities, transition, quality-of-life, personal resources.
1. Background

Several studies have indicated that adolescents with disabilities are more dissatisfied with their quality of life (QoL) in comparison with their nondisabled peers (Edwards, Patrick, & Topolski, 2003). For example, Sacks and Kern (2008) examined quality of life differences between adolescent students with disabilities and found that these students are significantly more dissatisfied with their overall quality-of-life (QoL), as well as in the subareas assessed: self, relationships, and environment, than their non-disabled peers. Also, Watson and Keith (2002) found that students with disabilities receiving special education services in public schools scored lower than nondisabled students on four QoL factors measured (satisfaction, well-being, social belonging, and empowerment/control).

One of the reasons why it is critical to improve quality of life is their impact on the future life of the young people with disabilities (Wolf-Branigin, Schuyler, & White, 2007). In fact, more than their non disable peers, youth with disabilities have difficulties in successfully making the transition from adolescence to adulthood and then from school to work (McCollin & Obiakor, 2010). In this respect, Halpern (1993) refers that transition as an outcome-oriented process that leads to employment as a narrowly defined goal of transition. So, the authors conceptualized transition as an outcome-oriented process leading to quality of life for individuals with disabilities.

In this sense, concepts related to QoL emerge as very important in development and future life of persons with disabilities. For example, the concept of self-determination is theoretically linked with QoL and is a critical skill necessary for a successful navigation to the adult life that permit the individuals with disabilities to be responsible for making their own choices in life (McCollin & Obiakor, 2010). In fact, there are key findings and conclusions that support the application of the QoL concept in the field of special education (Verdugo & Schalock, 2009). Current and ongoing research in this area has identified eight core QoL domains, that is, a set of factors composing personal well-being (Schalock, 2004): 1) emotional well-being; 2) interpersonal relationships; 3) material well-being; 4) personal development; 5) physical wellbeing; 6) self-determination; 7) social inclusion; and 8) rights. Some of these QoL domains proposed by Schalock (2004) have been reported in studies as personal factors which impact successful transition processes and that emerge as crucial to achieve a state of overall well-being through the empowerment of people with disabilities. For example, training in specific vocational skills, daily living skills training and self-determination training are identified as successful transition practices and suggested by the literature (Johnson, Stoddlen, Emanuel, Luecking, & Mack, 2002; Landmark, Ju, & Zhang, 2010; M. L. Wehmeyer & Palmer, 2003). Social skills training also seems to be important not only to the transition processes but also for employment success. Employees with disabilities can became more socially, competent, interactive and included in the social network of the workplace through a social skills program training (Goetz Robert Gaylord-Ross, Hyun-Sook Park, Stacey Johnston, Lee, & Goetz, 1995). Attitude of youth with disabilities toward their future and work is another factor with implications on future outcomes. Thus, the readiness and motivation exhibited by the young person to move forward in life appears to affect the transition success (Halpern, 1994) indicating the need for early intervention services with adolescents who have disabilities to improve their attitude toward work and quality of life (Wolf-Branigin, et al., 2007).

Referring to transition processes, there have been several studies with youth with disabilities making the transition from school to work and adult life that inform about important interventions that promise positive impact on transition outcomes. Generally transition refers to a change in status from behaving as a student to assuming emergent adult roles in the community (employment, participating in post-secondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships). Many influences appear to affect this transition including the quality and impact of the student’s high school program, the nature and quality of transition services that are provided to the student and his or her family, opportunities in the community that are actually available for the young person (Halpern, 1994). For example, having paid work experiences during the last years of secondary school is a factor associated with successful post school employment outcomes (Luecking & Fabian, 2000; Wagner, Newman, Cameto, & Levine, 2006). There is emerging evidence to suggest the value of student empowerment to participate in and make informed choices about transition planning. The most popular strategy used to prepare secondary students with high-incidence disabilities for life after high school is one in which the student attends, contributes to, and assumes some responsibility for the
Individual Educational Program and Transition Plan (Martin et al., 2006). Moreover, when secondary students with high-incidence disabilities participate in their transition and educational planning meetings as active members with responsibilities, they are more motivated (Skouge, Kelly, Roberts, Leake, & Stodden, 2007).

Given the link between QoL and adult outcomes this study attempts to understand the extent to which some QoL domains are linked with both their actual situation of life and expectations for the future. So, through a qualitative research this study intends to examine the perspectives of youth with disabilities who are institutionalized about their life-satisfaction and personal capacities. Additionally, identifying from youth about their past experiences in school related to the transition preparation process and identification of barriers as well as facilitators youth perceived as having an influence in their current life.

2. Methods

A focus group with four youth with disabilities was used as the source for data collection in this qualitative study. Qualitative research methods such as focus groups hold the potential to give to people with disabilities the opportunity to participate as active partners in the research process rather than just as a person who simply shares their experiences, and answers questions about why and how a particular phenomena is being perceived and experienced (Kroll, Barbour, & Harris, 2007).

Participants

For this study, one focus group was organized to represent the viewpoints of young adults (ages 23-43) with physical disabilities and institutionalized in a rural area in Portugal. Focus group participants were selected using convenience sampling. The participants included four young adults (1 male and 3 female) with mobility impairments. All were living at home with their families. Within the participants, three of them (participant 1, 2 and 3) had some type of activities in community a few hours per week. The other one, with more severe disabilities (participant 4), did not do any kind of work outside of the institution. Participants 1 and 2 had taken a technical computer course. The participant 3 was planning on moving out of the family house to a big city (residential house) with the aim to pursue studies in college. Table 1 provides an overview of participants' characteristics.

Table 1. Characteristics of focus group participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Grade</th>
<th>Age</th>
<th>Gender</th>
<th>Present occupation</th>
<th>Mobility device/ others difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>12th</td>
<td>32</td>
<td>M</td>
<td>Occupational Activities</td>
<td>Crutches</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Work some hours per week in sheltered environment</td>
<td></td>
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<tr>
<td>2</td>
<td>9th</td>
<td>33</td>
<td>F</td>
<td>Occupational Activities</td>
<td>Wheelchair</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Work one morning per week in community</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>12th</td>
<td>23</td>
<td>F</td>
<td>Occupational Activities</td>
<td>Wheelchair</td>
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<td></td>
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<td></td>
<td></td>
<td>Work one morning per week in community</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>4th</td>
<td>43</td>
<td>F</td>
<td>Occupational Activities</td>
<td>Wheelchair Speech difficulties</td>
</tr>
</tbody>
</table>

Procedure

The focus group session addressed questions intended to identify barriers and facilitators in environmental and personal domains that influence QoL and future plans of youth with disabilities. The topics presented for discussion in the focus groups were based on literature relevant issues which have been shown as having an influence in the transition process. The content questions for this research study were organized around three broad research questions: (a) What are youth’s perceptions of QoL and personal capacities? (b) What types of visions for the future
do students with disabilities possess? (c) What school experiences do young adults with disabilities have in the past related to transition planning? The focus groups met for two sessions, lasting 1.5 hours each. The two meetings were audiotaped and were transcribed. In the room were only the interviewer and the participants.

**Analysis**

The audio tapes were transcribed verbatim by the interviewer. The process of text analysis included: (a) coding through segmenting and labeling text to form descriptions (b) aggregating codes together to form a major idea in a broad themes through the process of eliminating redundancies. (b) Layering themes organizing themes into layers from basic to elementary themes to more sophisticated ones (Creswell, 2008).

3. Results

The results of this qualitative study revealed a number of personal and environmental barriers and facilitators related to future plans and quality of life. Six major themes were identified: (1) attitudes towards the future; (2) related psychological factors; (4) opportunities in school; (5) opportunities in the community; (5) social environment; (6) assistive technology. After the identification of the themes, facilitators and barriers were organized into four additional categories: (1) personal facilitators; (2) personal barriers; (3) environmental barriers; and (4) environmental facilitators.

**Personal factors - Facilitators**

**Attitude to the future**

The expectation and confidence in the future emerged as a facilitator to have future goals and undertake actions in order to obtain them. From the four youth interviewed, only one had plans for continue to study and get an employment.

“I make plans and I take actions. I feel confidence, my life is changing. Recently someone called me from a residential home, where I was on the waiting list, and asked if I was interested; I immediately said yes! I want to study and then work as a translator”. (Participant 3)

**Related psychological factors**

Relative to their own capabilities, youth self-knowledge and acceptance of disability emerges as a facilitator to self-efficacy and making the right choices in life.

“I know myself, I have confidence in me, I know what I can do and what I can’t do. For example, I decided not go to math exam at high school because I struggle with it. So, because I had other options, I decide not go through a way that I know I’m not be able to.” (Participant 3)

“If someone tell me to go to College I said no because I know my capacities ... I have skills to work with computers.” (Participant 1)

“There was a time that I didn’t accept my disability but now I accept it and I feel I have capabilities.” (Participant 2)

The only participant with work and study plans for the future currently lives in an unfavorable environment at home and has transformed this adversity into an opportunity to leave home and expand her life.

“I do not feel safe at home. When I grew up I began to realize that there were many things wrong with my family and I started thinking about leave home.” (Participant 3)

**Personal factors - Barriers**

**Attitude to the future**

...
The low expectations and lack of defined future goals are evident for three participants. Two of them expect that aspects related with future job or employment probably are not going to change too much.

“I have doubts; do not know how it goes. I’m thinking taking the driving license and treating my teeth.” (Participant 1)

“I live one day at time. I don’t have plans in the short term or long term because I think if we make plans and they do not materialize we get frustrated. I think that I will continue to work on the company where I am now once a week.” (Participant 2)

The participant with more severe limitations doesn’t have any expectation that something can change in her life.

“I don’t have plans, nothing new happens to me.” (Participant 4)

Related psychological factors

One message to emerge from transcript analysis is that different conceptions and connections with family significantly influence the choices made by participants relatively to their lives. The family dependence and lack of emotional autonomy to live apart from family for two of participants were the reasons why they did not want to leave their current residential situation to another one where they can have more opportunities.

“In the institution where I had therapies they advised me to take a technical course out of my village…but I didn’t want…it is sad, but I cannot be far away from home.” (Participant 1)

“I don’t want to get away from home...for now…” (Participant 2)

Sometimes the support by others, friends and parents, seems to be a factor that can lead young adults with disabilities to feel comfortable and resistant to changes in their lives. Three participants do not see themselves as changing their life situation because they currently feel safe and supported by others which can also become a barrier.

“When I took my computers course I lived in a Residential away from home. My mother wanted that I stay there because of the opportunities to work, but I didn’t want to. I miss my parents and my brother.” (Participant 2)

The emotional factors were mentioned when were asked what they feel about life. Being afraid, anxious and feel alone were mentioned as constraints to QoL.

“I feel somewhat alone but I’m happy... I have a computer that gives me distraction.” (Participant 2)

“I think I am happy... Although I have some fears, I’m on alert all day …” (Participant 1)

“I’m always nervous. I’m not sure why I feel that way.” (Participant 4)

When it comes to the issue how they do choices in their lives, one participant referred fear when making choices is needed.

“I make my choices …but I’m very nervous and I have fears” (Participant 1)

When asked if they do choices in their lives, three participants referred feel pressure at home.

“I feel pressured by others at home; I can’t move and decide anything. I never learn to fight for what I want because I’m too overwhelmed.” (Participant 4)

“I make some choices, but I can’t decide about little things in my daily life at home.” (Participant 2)

When asked about what would improve their lives, make their own choices in life was referenced by another two participants:

“Make all decisions of my life, take control over my life, basically is that.” (Participant 3)

Environmental factors - Facilitators

Opportunities in Community

Participants identified opportunities in the community as an important factor for planning and realizing future life goals. For example, the participant who is moving to the city now has the chance to realize her future goals.
“I’m moving to a big city. I think I will have more chance to study and work there.” (Participant 3)

Previous work experiences seemed to be an opportunity that provides self-efficacy and self-realization.
“I worked one morning a week and I’m enjoying it. For the first time in my life I’m earning money, and do something only by myself” (Participant 2)
“I took a technical course about computers and then I worked for one year on this. I have capacities with the computer, computers are my life.” (Participant 1)

Have opportunities in the community to take the role of helping others rather than been cared for, or always being the helped person, was referred as a happiness and empowering factors.

“Sometimes I work as volunteer ... I feel happy and helpful when I can help others”. (Participant 1)
“I am held to help others and I’m very capable of it. I feel accomplished when I help others.” (Participant 2)

**Social environment**

Another point that emerged from the focus groups is the important role of the support given by therapists relatively to individuals future goals.

“When I was a teenager I was very tight I thought nothing was right with me, I couldn’t find ways to spread my wings. Later I matured and with the help of others, especially the support of a therapist, I chose my way”. (Participant 3)
“A therapist told me to persecute studies”

When asked about their actual quality of life and happiness perception, all participants responses were focused on their close relationships. Overall, having friends and family, and to be autonomous in terms of mobility (be free to go out) were cited as factors contributing to quality of life.

“I guess I’m happy... I have family and friends around me, I have my scooter so I can leave when I want” (Participant 1)
“Yes I’m happy... taking the part of wanting to get out more ... I would like to go out with friends by my self... but I’m happy, I have my family with me.” (Participant 2)

**Assistive Technology**

Computers seem to have an important role in life of the participants. Two young adults refer to the use of computers with strong feelings.

“Computers are my life, I have to use the computer every days.” (Participant 1)
“Sometimes I fell alone, but I have my computer to distract me.” (Participant 2)

**Environmental factors - Barriers**

**Opportunities - School**

The lack of school support in transition and employment preparation was evidenced by all participants. None of the participants identified their school experiences as having a significant impact on career aspirations. All participants referred never had any kind of preparation addressed to transition to adult life. They never worked while in school and they also never attended an Individualized Educational Programs meeting. Three participants received some guidance from therapists in the institutions where they had therapies.

“...the school that guided me most was the “school of life”...what was happening to me, things I see and heard” (Participant 3)
“I never attended a meeting, only careers meetings after turning 18...I used to talk with a psychologist but about the present, not about the future” (Participant 3)

**Opportunities - Community**
The lack of opportunities in the community and limited employment services has risen as an issue when was asked about their own capabilities and skills. In general all the participants expressed feelings that their skills are being wasted. Moreover, they argue that living in a rural area results in no employment opportunities.

“If I lived out of here I could have a job and take the drive license” (Participant 1)

“On this environment I can’t develop myself so much, there aren’t many opportunities. One day an employer called me but they didn’t know that I am in a wheelchair. It was in a grocery store, when they saw me, that they told that is was not possible for me to work there.” (Participant 2)

The four participants agree about the lack of opportunities. However it should be noted that the above two statements are from participants who currently work once a week, and are the same participants who do not want leave home to pursue more opportunities. It seems that the work experiences have not influenced these participants in defining their goals and improve their current work situation.

Social environment
An environmental barrier identified by all participants was related to school discrimination experiences. The discrimination experiences were related to lack of acceptance by peers, including being taunted and disparaged and also lack of support by teachers and bureaucratic problems.

“My colleagues used to making fun of me.” (Participant 4)

“Usually they didn’t wanted us as part of their work group.” (Participant 2)

“The law in school was always changing.” (Participant 1)

“In elementary school my teacher always put me drawing.” (Participant 2)

However, they also mentioned that there were some years in school that things went well and was a good experience. These positives experiences are related with the existence of friends and acceptance by peers.

Assistive Technology
The theme mobility and lack of access to assistive technology as a barrier is clearly evident for all participants. For instance, the desire to have better mobility devices were expressed as a hope or an expectation to the future coming up plans.

“In the future, I would like to have a better wheelchair and an device that allow me to go to bed and bathroom by myself” (Participant 2)

Also when it came to what capacities would make for them to go further in life, the independence in moving the wheelchair or a better wheelchair emerged from two participants:

“I would like to travel in wheelchair by myself and move around without anyone having to push me like my colleague.” (Participant 4)

“I’m independent with my wheelchair but I still not satisfied because I would like to have a lighter one, with a sporty look that allows easy movements.” (Participant 2)

4. Conclusions

When working with young adults with disabilities, it is important to consider the environmental and personal factors that influence youth’s QoL and future expectations. The attitude towards the future expressed by youth and adults with disabilities permits a better understanding about what can limit or improve their ever developing future. Our qualitative analyses identified various personal and environmental barriers and facilitators for a successful transition planning from school to adult life for young adults with physical disabilities.

The personal facilitators identified are related to expectations and confidence that youth feels to have in their future. By contrast, low expectations and lack of defined goals may constitute barriers to improve individual situations and life goals. To face these attitudinal difficulties, Wolf-Branigin et al. (2007) suggests the need for early intervention services with adolescents who have disabilities to improve their attitude toward work and quality of life. In these sense they suggest that intervention components should to build resilience using a strength-based perspective to prepare adolescents who may face severe difficulties as they reach adulthood and increase their likelihood of becoming self-sufficient. The sense of self-efficacy seems to be a resiliency factor for youth with
disabilities face negatives life events and reach well-being. For example, Simões, Matos, Ferreira and Tomé (2010) conducted a study with a sample of adolescents with special educational needs and found that high levels of self-efficacy can moderate the impact of negative life events in well-being. In fact, one of participants from this research study who shows to have a sense of self-efficacy also shows the capacity to transform adversity in an opportunity. Barriers related to youth-related psychological factors were found linked to emotional dependence from family and lack of autonomy that can lead to some resistance to change. Still at psychological level, emotions like fears, loneliness and anxiety emerge as a barrier to QoL. These results lead us to previous studies where was highlighted the important role of expectations of significant adults and loneliness in life satisfaction (Canha, 2010).

Related psychological aspects that may act as facilitators in both future expectations and quality of life were also identified. Thus, the acceptance and understanding of the impact that disability has, as well as the self-knowledge, emerges as facilitators to make right choices and to develop sense of self-efficacy. These facilitators are important factors to a self-determined behavior which is one of the personal skills far proven as an important educational outcome to youth with disabilities to achieve positive adult outcomes after they leave high school (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997) and to enhance QoL (Lachapelle et al., 2005; Wehmeyer, 1996). These findings reinforce the need to promote self-determination behaviour during the transition process (Carter, Trainor, Owens, Sweden & Sun, 2010). Student involvement in educational planning can lead to enhanced transition knowledge and skills about transition planning but the benefit is reciprocal: by promoting student involvement educators can enhance self-determination, and by promoting self-determination educators can promote student involvement in their planning (Lee et al., 2012). As discussed previously, the student involvement is critical to prepare students with high-incidence disabilities for life after high school (Martin et al., 2006). Moreover, Lee et al. (2012) found that self-efficacy and outcome expectancy for transition planning were both important variables that significantly predicted high self-determination scores (Lee et al., 2012). So, seems that self-efficacy is an important factor to a self-determined attitude as it is to a resilience behavior as we have seen above.

Social and environmental facilitators emerged as a link to both future plans and QoL. Close relationships as having family support, friends and being able to go out with them, were identified by participants as important factors to improve their QoL. Moreover, the support given by therapists seems to have an important place for making choices about future life. These findings suggest the importance of social connectedness for adolescents with disabilities (Edwards, et al., 2003). Social support, whether from the family or significant others outside the home, can be an important influence on the QoL of adolescents with disabilities (Emmond, Fortin, & Picard, 1998).

The lack of opportunities to make choices felt by participants in their daily live was a barrier for the development and attainment of future goals. In addition, making their own choices in life was referenced by participants as an important aspect to improve their quality of life. So, from a personal perspective, helping individuals with disabilities to reach a higher level of quality of life may require to teach the person how to choose, since personal choice is the underlying requirement for addressing quality-of-life issues (Halpern, 1993). In fact, according Brown and Brown, (2009) the availability of opportunities and decision making for choice among persons with disabilities and their families seems to be other essential component of QoL. These authors considered choice to be a fundamental aspect of quality of life, since it is the outward manifestation of an individual’s personal wishes and life orientation. Even in the case of individuals with more significant disabilities, even if choices and opportunities are limited, some aspects of life can always be self-directed to support a desired quality of life (Wehmeyer, 1996).

Assistive technology can play an important role in life of people with physical limitations. For one hand, computers are a mean to access an outside world that they can’t access by themselves and thus be a facilitator of well-being. On the other hand, the lack of access to assistive technology, particularly those who facilitate the mobility of people with physical limitations, can be a barrier to the autonomy and QoL of people with these kinds of limitations.

One limitation of the study was the sample size and the fact that they all resided in rural areas. It would be difficult to generalize to adolescents with disabilities living in urban or suburban settings, or in rural areas in other parts of the country. Covering information in these areas can be an opportunity for future research. Given the purpose and nature of qualitative research methodology, the purpose of this research is not to generalize these results to all youth with disabilities. Rather, these results give voice to students’ perspectives concerning their quality of life and future perspectives and relate that with past experiences. As suggesting by others authors, more research is needed regarding the impact of vocational programs on career aspirations for youth with disabilities. In particular, further investigation is needed to determine how school and community experiences assist in or discourage youth
with disabilities from making positive career decisions bearing in mind their quality of life and a healthy personal development.

Knowledge of the QoL factors and personal resources that influence individual’s present life, from the perspectives of the young adults, provides information that can be used to design programs and supports to empower people with disabilities to better achieve an independent life with quality. Despite the barriers identified seems essential to focus attention on personal resources of these young people. Thus, youth with disabilities should be supported in order to develop the skills, attitudes, and motivation necessary for successful career development. In this sense, professionals need to provide early interventions that incorporate the promotion of critical skills, as self-determination and self-efficacy, into career education and employment preparation.

References


