Quality of Life for People with Autism Myth or Reality. A power point presentation from the Living Autism Conference 2013

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Aim of the Autism Strategy

The central aim of the Autism Strategy is to commission effective services of the highest possible quality, led by the level of demand and the needs and desired outcomes of people in (Cornwall). This is intended to improve the ***quality of life*** and ***well being*** of the people that use services, their families and carers.

(Cornwall Strategy Document)

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Definitions of Quality of Life

- "Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns

(1995 (WHOQOL, 1995)

quality of life as concerned with how "impairment limits a person's ability to fulfil a normal role."

Carr, Gibson, & Robinson (2001)

Quality of life is individually defined

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Quality of life Indicators (Mesibov)

1. Emotional wellbeing
2. Interpersonal wellbeing
3. Material Wellbeing
4. Personal development
5. Physical development
6. Self determination
7. Social inclusion

Unpublished Paper NAS Professional Conference.

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(1) What Contributes to Emotional Wellbeing

- Recognising emotions in self and others (thoughts and feelings)
- Managing anxieties and stress (being stress free)
- Feeling good about yourself (having a positive self concept)
- Having Cognitive strategies for life
- Happiness

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(1) Emotional Wellbeing

- Research studies have indicated that mental health difficulties may occur more often among adults and adolescents on the autism spectrum (e.g. Howlin, 2000; Stewart, Barnard, & Pearson, 2006;

- In a review of case studies on depression and autism by Howlin (2000) identified a 41% prevalence of depression among autistic individuals.

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(2) Interpersonal Wellbeing

- Relationships with peers with and without autism, sex education
- Special relationships
- Learning to be with others , one to one, small groups larger groups
- Being engaged in different types of activities with people
- Kindness, gratitude, forgiveness

(2) Interpersonal Relations and Wellbeing

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- Growth in interpersonal relations during adulthood (and adolescence and childhood) involves developing friendships, romantic relationships, and other social relationships. Diverse difficulties and strengths in language, communication, and social interaction constitute a major facet of the disability of autism. Consequently, it follows that challenges in forming and maintaining social relationships would likely present for autistic adults. Numerous academic studies suggest that this is the case (e.g. Hurlbutt & Chalmers, 2002; Orsmond, 2004; Sperry & Mesibov, 2005).

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(3) Material Wellbeing

- Having a job
- Understanding money and earning money
  Prioritising spending
- Having your own place to live
- Having and looking after possessions

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Temple Granding Having a JOB

Work is more than just a livelihood or pay check, it is the key to a satisfying and productive life. For many on the autistic spectrum it is the glue that keeps life together in an otherwise frustrating and sometimes confusing world. Certainly my life would not be worth living if I did not have intellectually satisfying work.

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Real Work
Chocolate Memories
Autism works
social enterprise
Lettuce Works

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Housing

Housing:

- People with autism should have choice over where they live and who they live with, including developing housing options (DOH 2009b).
- Almost half of adults with autism over 25 continue to live in the family home and over half are dependent on their parents for financial support. (Push for Action. NAS)

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(4) Personal Development

- Understanding and experiencing self
- Understanding my autism
- Being independent
- Being self sufficient
- Developing and growing

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Personal Development What Individuals with Autism Say

- They told us they need help with washing and dressing 36%
- preparing a meal (63%),
- doing housework (73%),
- shopping (68%),
- paying a bill or dealing with letters (83%)
- managing money (77%),
- but in the majority of cases they are unable to access this help from their local authority.

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(5) Physical Wellbeing

- Understanding the need for physical wellbeing
- Getting fit staying fit
- Having a plan
- Looking after physical health
- Eating a balanced diet
- Hygiene and body care
- What I do for fun and enjoyment:
- Visiting and socializing
- Casual leisure activities
- Hobbies

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Gorge Scrambling

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(6) Self Determination

- Having control over my life
- Being able to set your own goals
- The right to express your autism.
- Choices Understanding about choices and Making choices including making the wrong ones.

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(6) Self-Determination

Communication skills constitute an essential component of self-determination and self-advocacy for people with and without disabilities. Without adequate access to a working means of communication, it is not possible to sufficiently convey the individual wants, needs, and preferences that guide a person's self-direction and decision-making.

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(7) Social Inclusion

The success of living well independently in communities appears to rest on three main factors acting together (***Quality of Life ❖ Dream or Reality?*** p.131*):*

- the presence of adequate community agency support;
- acceptance of people with developmental disabilities by the general population of the community (including policies and laws requiring acceptance and discouraging discrimination); and
- the availability of financial resources to ensure that people with developmental disabilities can access a reasonable standard of living enjoyed by other members of the community.

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(7) Social Inclusion

In recent research carried out by The National Autistic Society, 70% of adults with autism told us that with more support they would be less isolated.

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(7) Factors Affecting Social Inclusion

Physical Belonging	Where I live: •Place of residence •Space for privacy •Living in a neighbourhood
Social Belonging	The people around me: •Having a spouse or special person •Family •Friends
Community Belonging	My connectedness to the resources in my community: •Access to meaningful work •Access to community places •Access to education

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Barriers to Quality of Life for Individuals with Autism.

The National Audit Office survey34 identified not only the poor quality of life experienced by many adults with autism but also the inefficient use of public money. National initiatives (such as the current Autism Bill and cross-government autism strategy) have been developed in response to the injustice experienced by many adults with autism. Local authorities and PCTs now have a responsibility to seize this opportunity to make better use of public money in order to achieve better outcomes for adults with autism. Good practice in supporting adults with autism: guidance for commissioners and statutory s

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Barriers to Quality of Life for Individuals with Autism

(1) Emotional Wellbeing

- Lack of understanding even amongst professional
- Lack of awareness and training
- Only a small number of professional guides and handbooks on the subject of mental health autism.
- Lack of appropriate support for the individual with autism.

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Barriers to Quality of Life for Individuals with Autism

(3) Employment: People with autism should be supported into work and supported to remain in work (DOH 2010d).

only 15% of adults with autism are in paid employment compared to 48% of people with general disabilities22. A much greater number of people with autism want to work and could do so if able to access appropriate support.

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Barriers to Quality of Life for Individuals with Autism

4 Personal Development

Education and 'getting a life': People with autism should be able to access education, transport, social and leisure activities and supported when forming new relationships and becoming parents (DOH 2009b).

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(5) Barriers to Quality of Life for Individuals with Autism

Physical Wellbeing

This situation often becomes naturalized as a false belief that all autistic people have a strong aversion to participating in social recreational opportunities, a misperception that may then deter community organizations from modifying their recreational programs to enable autistic people to participate.

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Barrier to Quality of Life for Individuals with Autism

- **Self Determination**

Another major barrier to the achievement of self-determination for autistic people is a fundamental assumption held by many professionals that self-determination is not attainable or desirable for autistic people. This assumption is based on rigid belief systems throughout the disability service-delivery community about what constitutes self-determination for people with disabilities.

by SM Robertson - 2009 -

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Barriers to Quality of Life For individual with Autism

- **(7) Social Inclusion**

Historical stigma and continuing myths and stereotypes about autism have stifled the social acceptance of autistic people and their full inclusion in community life. Broderick & Ne'eman (2008) and Robertson & Ne'eman (2008) describe how many demeaning and dehumanizing metaphors about autistic people have persisted despite considerable efforts by the autistic self-advocacy and allied community to counter them. Neurodiversity,

***Quality of Life*, and *Autistic* Adults: Shifting Research .**
by SM Robertson - 2009 -

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Diffic.ulties Accessing Support

Many adults with autism are unable to access the support they need, which leaves them isolated and vulnerable. This lack of timely appropriate support can result in unnecessary mental health deterioration and reliance on high-cost acute services. The right support at the right time can have a significant positive impact on quality of life, outcomes and value for money.

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What Individuals with Autism Say

- The level of support that adults with autism need varies greatly. Just 7% of respondents to our survey said they need no support. 40%, however, need at least 30 hours a week, including 25% who need 24-hour care.**8**
- Low-level support can make all the difference between leading an 'everyday' life and falling into a crisis." *(Parent)*

Impact of lack of support on families and carers

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Lack of support can have a massive impact on the lives of family members. Of those who are not receiving the level of support they need from social services, 77% said they were relying on parents and 22% on friends to provide that support.17

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Impact of Lack of Support on Parents and Carers

- 70% of carers responding to our 2012 survey said that
- they often feel isolated, 61% said that it has put a strain
- on their marriage or relationship, and 52% said it has
- negatively affected their mental health.
- Furthermore, two thirds of carers say that being a carer
- has had a negative impact on their work life, with 20%
- saying they had to reduce their hours and 17% that they
- had to give up work altogether.18

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- Neurodiversity, *Quality of Life*, and *Autistic* Adults: Shifting Research ...
- *dsq-sds.org* › Home › Vol 30, No 1 (2010)Cached
- Similar
- by SM Robertson - 2009 - Cited by 11 - Related articles
- Neurodiversity, *Quality of Life*, and *Autistic* Adults: Shifting Research and Professional Focuses onto Real-Life Challenges*Quality of Life* indicators - Ontario Adult *Autism* Research and ...
- *www.ont-**autism**.uoguelph.ca/STRATEGIES4.shtml*Cached
- Similar
- A major study by the Centre for Health Promotion of the University of Toronto, published in 1997, defined *Quality of Life* as the degree to which a person enjoys ...
- 16Bancroft et al (2012). Op cit.
- 17The National Autistic Society (2013). *NAS survey for Push for Action campaign*
- 18Bancroft et al (2012). Op cit.

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References

- Department of Health (2010d) 'Fulfilling and rewarding lives': The strategy for adults with autism in England (2010). London: Department of Health
- Department of Health (2010e) Implementing ''Fulfilling and rewarding lives'': Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy. London: Department of Health

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If you need help looking for services for an individual with an autism spectrum condition, we can help. Click below for the Autism Placement Support Service.

Click here for our
Autism Placement
Support Service