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**RESEARCH AND INNOVATION  
IN SOCIAL CARE**



# RESEARCH

- Participating in and organizing national and international conferences on the improvement of services
- Adopting an international outlook which helps us to identify global research and best practice that can be applied within our services.
- Focusing on the role of research and development in creating and maintaining specialist services.


# IX International Autism-Europe Congress 2010, Catania, Italy

## IX INTERNATIONAL CONGRESS AUTISM EUROPE - A Future for Autism

Catania, 8-10 October 2010

### DESIGNING AN AUTISM-FRIENDLY ENVIRONMENT IN A RESIDENTIAL SERVICE FOR ADULTS WITH AUTISM

Castro, Herculano ([hcastro@mentaur.it](mailto:hcastro@mentaur.it)); Mukherji, Shekhar; Melo, Isabel; Silva, Silvia



The environment in which a person with autism lives can have a major impact on their wellbeing. Being aware of the sensory difficulties faced by people with autism, we have designed LAVANDA VILLA, a small specialist house to provide adults with autistic spectrum disorders with a home which complies with their needs and understands their singularity.

- Fluorescent or harsh lighting was replaced by soft and adjustable lighting.
- The ceiling in the lounge was lowered in order to reduce noise levels, specifically echoes.
- Low arousal colors were used on the walls and patterned wallpaper was avoided.
- Maintaining an intensive and consistent autism orientated staff training and development program.
- Working towards becoming an Autism Accredited Service.
- Enhancing an open door policy.
- High staff ratio.



- Radiators were boxed in to eliminate the risk of people getting burnt and to reduce the amount of noise generated if they are hit.
- To reduce the possibility of self harm, ordinary glass was replaced by strengthened safety glass or covered with plastic.
- A resistant yet cozy carpet was installed in the floor, avoiding strong patterns and facilitating a smooth navigation within the house areas.
- All sharp edges were softened.
- An outdoor working area was created in the garden.



- Support each service user to access the community both at a local and national level.
- Adults with autism spectrum disorders seeking to improve their independent living skills are encouraged to aim to move on to more independent forms of living.
- In parallel, an open working space is being created. A community resources centre where people with autism will be able to enhance their skills whilst delivering a quality service to the community.
- A staff team committed to assist and support people with autism in calculated risk-taking.

- The individualization of the bedrooms and common areas is actively encouraged.
- An activities room is available and will be tailored according to the service users' needs and interests.
- Furniture, furnishings, equipment and consumables are 'non-institutional' in design.
- Each person with autism is supported by a tailored individual person centered care planning.
- The house location was thoroughly assessed and it lies within a short walking distance of several public services as well as from a green park.

The knowledge and understanding of autism spectrum disorders consistently informs the organisation, resources and management of the service and the individual assessment and planning as well as all aspects of practice. By providing a consistent quality service for all service users in a structured, caring and family atmosphere, we expect that the people with autism who will use this service will push back their boundaries and limitations to live a more varied and rich life as fully-fledged citizens of their community





# Dementia in Learning Disability: a 21<sup>st</sup> Century Challenge

## Dementia in Learning Disability: a 21<sup>st</sup> Century Challenge

Friday 12 November 2010  
Doubletree by Hilton, Milton Keynes



Photo by iStock

Find out more and book online at [www.bild.org.uk/events](http://www.bild.org.uk/events)

# NAS Professionals Conference 2012

National Autistic Society's Professional Conference – Working Together for Better Outcomes  
Manchester, 28-29 February 2012

## DEVELOPING AN OBJECTIVE TOOL TO MEASURE QUALITY OF LIFE OUTCOMES OF PEOPLE WITH AN AUTISM SPECTRUM DISORDER (ASD)

Castro, Herculano (hcastro@mentaur.ltd.uk); Mukherji, Shekhar; Cuesta, Jose Luis; Merino, Maria



Robert Schalock defined quality of life as a concept that reflects the conditions of life desired by a person in connection with eight basic needs: emotional well being, relationships, material welfare, personal development, physical well being, self determination, social inclusion and rights. Validated and reliable tools to measure the quality of life outcomes of individuals with ASD are in short supply. The difficulty in assessing these outcomes in persons with ASD from a subjective perspective, make it necessary to find valid objective quality of life indicators. Mentaur is developing a U.K. specific instrument, in collaboration with the University of Burgos and Autism Burgos, Spain, who have been working in this field.

### OBJECTIVES

- To design an instrument made up of an objective guide of indicators to assess quality of life outcomes for persons with ASD.
- To adjust and validate this tool to make it U.K. specific.
- To provide this tool free of cost to all professionals and organisations who want to introduce quality of life based models in advancing and enriching the quality of support for persons with ASD.

SCORE	LEVEL
198 - 246	Excellent
149 - 197	Very Good
100 - 148	Good
51 - 99	Could be better
0 - 50	Could be much better

### METHODS

- The original tool was translated from Spanish to English and retranslated to Spanish to ensure accuracy. Certain cultural contextual changes were made. A qualitative research method, the Delphi technique, where a group of experts, co-ordinated by the chief researcher and through the successive sending of data, reach an agreed consensus is being used to validate the tool. A panel of experts has been selected from across the U.K. with members working in different roles within the autistic spectrum and a series of consultations are being carried out via email over a period of six months.



### RESULTS

- The instrument and application manual being developed comprises of indicators which drive outcomes and is grouped into 6 areas:



- Each indicator is made up of four evidences or tests which help evaluate and quantify the indicator.
- The preliminary results show that while there is concurrence with many of the indicators in several areas there is divergence which surround issues including information provided to users, extent of family involvement, level of choice, staff training and advocacy.

We believe there will be unique features to this tool which will surmount, for example, the serious communication difficulties which persons with ASD often have and will allow a comprehensive and objective overview on quality of life outcomes.






# My Life as I get older – age, autism and wellbeing

**My life as  
I get older -  
age, autism and wellbeing**

Advanced  
booking  
discount  
see inside

Friday 3 February 2012  
Doubletree by Hilton, Milton Keynes



Find out more and book online at [www.bild.org.uk/events](http://www.bild.org.uk/events)



# International Conference on New Technologies for People with Autism Spectrum Disorders (ITASD), Valencia, Spain

First International Conference on New Technologies for People with Autism Spectrum Disorders (ITASD)  
Valencia, 6-8 July 2012

## OTEA: Software designed to support the evaluation of quality of life outcomes in organizations for people with ASD

Cuesta, Jose Luis (joseluisuesta1@yahoo.es); Merino, Maria; Castro, Herculano; Mukherji, Shekhar

Robert Schalock defined quality of life as a concept that reflects the conditions of life desired by a person in connection with eight basic needs: emotional well being, relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights. Validated and reliable tools to measure the quality of life outcomes of individuals with ASD are in short supply. The difficulty in assessing these outcomes in persons with ASD from a subjective perspective, make it necessary to find valid objective quality of life indicators. As a tool to carry out efficient evaluations, technology plays an important role in the process of sharing good practice.

### OBJECTIVES

- To design an instrument made up of an objective guide of indicators to assess quality of life outcomes for persons with ASD.
- To develop a software program that facilitates the collection, analysis and interpretation of data.
- To adjust and validate the instrument in the UK.



SCORE	LEVEL
195-245	Excellent
140-190	Very Good
100-140	Good
51-99	Could be better
0-50	Could be much better

### METHODS

- A qualitative research method, the Delphi technique, where a group of experts, co-ordinated by the chief researcher and through the successive sending of data, reach an agreed consensus, was used to validate the Guide of Indicators both in Spain and the UK. A panel of experts was selected across Spain and later across the UK from a wide range of fields within the ASD and a series of consultations were carried out separately in both countries via email and over a limited period.

- The instrument and application manual comprises of indicators which drive outcomes and is grouped into 6 areas:



- Each indicator is made up of four evidences or tests which help evaluate and quantify the indicator.
- Alongside this process a software program was developed.

### RESULTS

OTEA is an IT program designed to map quality of life indicators according to their level of importance. It generates a visual picture of an organization's compliance with those indicators that helps to establish priorities when setting up goals and aims to improve the quality of life of people who use the service. This program also enables organizations to design person-centred plans across the institutional model.



- The OTEA program generates valuable information on the degree to which each of the markers (achieved, in process, not achieved) affect each indicator and their level of importance within the organizational chart. This information allows each organization to assess the level of quality of life and provides a framework for any improvement actions to be implemented.



We believe there are unique features to this tool which surmount, for example, the serious communication difficulties which persons with ASD often have and allow a comprehensive and objective overview on quality of life outcomes.



# Personalisation – A challenge for the Future, Porto Portugal



  
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03 MAIO

**PERSONALIZAÇÃO**  
Um Desafio de Futuro  
“Nada sobre mim sem mim”

Fundação Cupertino de Miranda, Porto





# **X Autism Europe International Congress 2013, Budapest, Hungary**

- ***Oral presentation***
  - *Developing an objective tool to measure quality of life outcomes of people with Autism Spectrum Disorders*

# INNOVATION

- Innovating to improve the quality of life of people who have autism.
- Developing technology which blends cutting edge computer hardware with autism specific educational software
- Designing premises
- Focusing on quality accreditation
- Safeguarding people from abuse
- Empowering people
- Types of services

# **Innovating to improve the quality of life of people who have autism**

- **Quality of Life – Schalock**

- Emotional Wellbeing
- Relationships
- Material Welfare
- Personal Development
- Physical Wellbeing
- Self-determination
- Social Inclusion
- Rights





# **Adapting a Guide of Indicators to measure quality of life of people with autism in the UK**

Mentaur Group

- Translation
- Validation

Autismo Burgos

University Of Burgos

- Review and support



- **Translation**

- Language issues
- Other adjustments

- **Validation**

- The Delphi method
  - Panel of experts
  - Consultations



## First Consultation

- GUIDE OF INDICATORS OF QUALITY OF LIFE
  - Contributions from the panel of experts





## Second Consultation

- LIST OF INDICATORS
  - Review
  - Score
    - Fundamental
    - Important
    - Of interest



## Third Consultation

- APPLICATION GUIDELINES
  - Submission and contributions

# **The guide of indicators of quality of life for people with autism**

- Quality referenced to the individual and needs assessment
- Setting and following up on personal development plans
- Staff training
- Structure and organization of service
- Human resources, materials and spaces
- Contact with the community and social empowerment






# Chart of indicators of quality of life

UK

UK	Individuals										Identifying needs			Staff training				Structure and organization						Resources	Community	
Fundamental interest	1	9					19					34		37	42								65		Fundamental interest	
	3	10					18								43											
	5	6													44											
															45											
High interest	2	8	11		14	17		20		24	32	33	36	39					51	53	58				High interest	
	4	7	12		15	16					30	35		38					54	57						
														41												
Medium interest				13					21	26	29			40		46	47	48	52		55	59	61	62	67	
									22	25								49	50		56			63		
										27																
Lower interest									23	28											60		64	68		
																								66		
	Physical wellbeing	Emotional wellbeing	Material welfare	Interpersonal relationships	Personal development	Rights	Self-determination	Social inclusion	Family perspective	Staff perspective	Planning	Care planning	Monitoring and evaluation plan	Autism awareness	Person centred planning	Attitudes and values	ASD research	Peer groups	Activities	Timetables	Communication / Coordination	Systematic evaluation of the service and its environment	Leadership	Human Resources, equipment and premises	Community access and social empowerment	
	Perspective of the person with ASD																									















# Assessment criteria

Assessment	Criteria	Score
Indicator not achieved	0 or 1 evidences met	
Indicator in process	2 or 3 evidences met	
Indicator achieved	4 evidences met	

# Chart of indicators of quality of life

UK	Individuals										Identifying needs			Staff training			Structure and organization					Res sour ces	Com mun ity																										
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Perspective of the person with ASD																																																	

# Score chart

Level	Score	No. of indicators	Multiply by	
Fundamental interest			5	
			4	
			0	
High Interest			4	
			3	
			0	
Medium Interest			3	
			2	
			0	
Lower interest			2	
			1	
			0	
TOTAL				

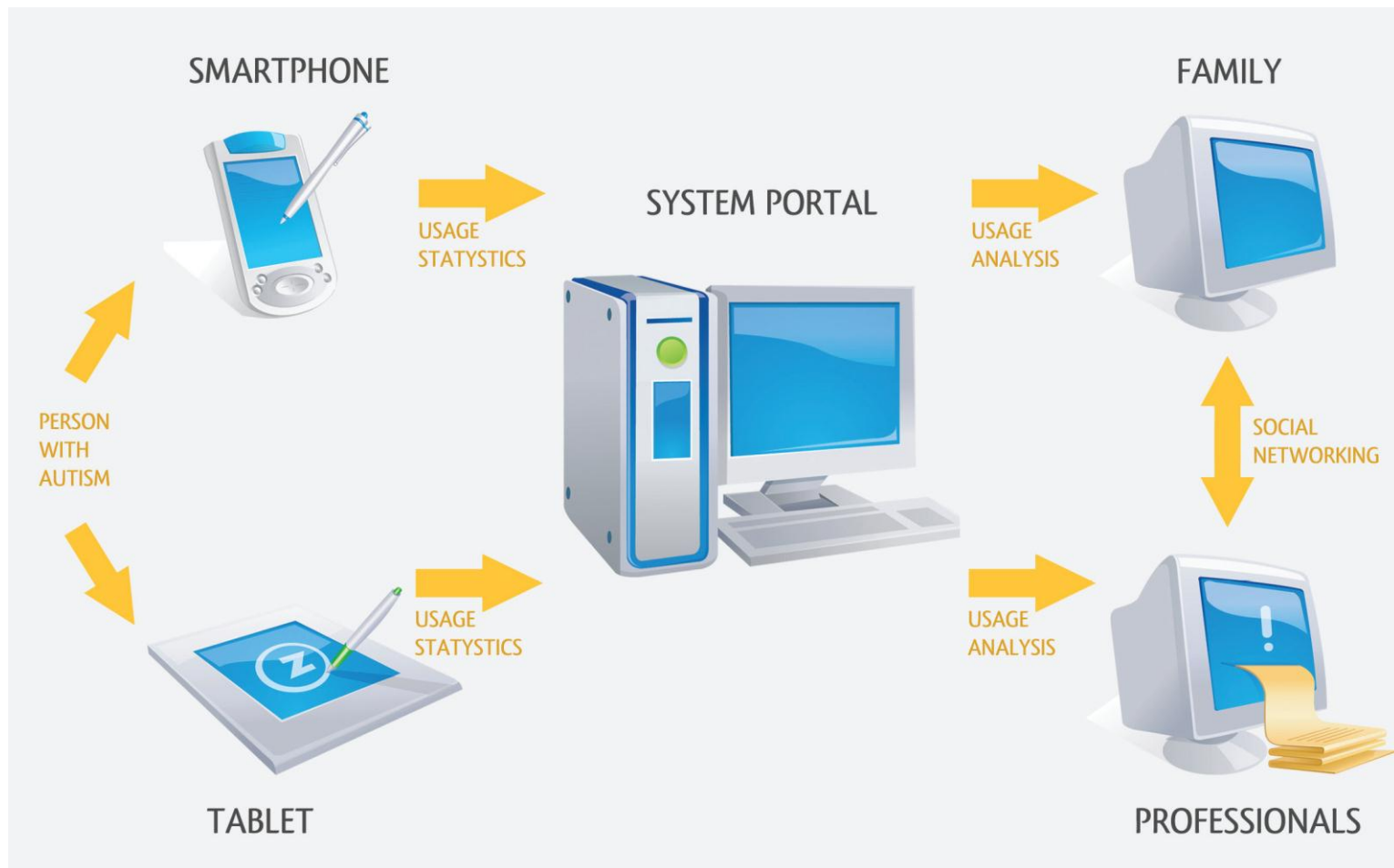




# Global score

SCORE	LEVEL
198 - 246	Excellent
149 - 197	Very Good
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0 - 50	Could be much better

# Developing technology which blends cutting edge computer hardware with autism specific educational software





# Designing Premises

Dementia Care Awards 2011

**Aurora House**  
Finalist **Best Interior  
Design Award**





## Focusing on quality accreditation




The National  
Autistic Society





# Safeguarding people from abuse



**ZERO  
TOLERANCE**

**ON  
ABUSE!**

This company operates in a **Zero Tolerance** on abuse!

**Abuse is Everybody's Business  
Safeguarding is our Responsibility.**



## **Empowering people**

- Get Connected Project
- Multimedia Advocacy Project

## Types of services

- Hybrid accommodation
  - Individual tenancies for people who are assessed as being capable of living within a more independent, but staffed environment.
  - Service users are supported to manage their own routines and housing-related responsibilities whilst living in a positive environment with their peers.



# The Mentaur Group Specialist Services

- **What is it?**
  - The Mentaur Group has been providing services to people with learning disabilities, mental disorder, dementia and autism since 1988. This has given us with a strong base from which to develop several specialisms in key areas.
  - We take the view that a specialist service does actually need to be special.





# What makes it special?

## **Our approach to specialisation**

- Specialisation taken seriously.
- Practises informed by specific policies depending on the different diagnosis
- Staff training
- Specific assessments
- Specialist strategies and methodologies



## • Dementia

- In-house serial measurement of cognitive functioning using recognised tools to get baseline functioning and track deterioration
- Life skills assessments at regular intervals to track any deterioration
- Life story work-to evoke and maintain memories and identity
- Special design and environmental features to both calm and stimulate different senses
- Intelligent systems to manage the service users environment

## • Autism

- Sensory issues taken into consideration prior to admission
- Sensory profiles for all service users
- Structured activities designed around individual service users
- Predictable routines
- Support plans that enhance flexibility of thought



## **Our approach to people who need support**

- Looking at the person more than the diagnostic label and, within a supportive framework, working with individuals to maximise their potential over the short and long term.



## **Our approach to staff**

- Identifying people as positive contributors to our specialist services due to their personality and their approach to their work.
- Equipping them with ongoing specific training and specialist supervision.
- Employing people that can demonstrate an ability to bring the best out of people who need support.





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# DISCUSSION