

**Autism Europe on Quality Assessment
PERSPECTIVES FOR A EUROPEAN ACCREDITATION SYSTEM FOR AUTISM**

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Introduction

Following the awareness campaign and consultation process via the web across the enlarged network of organisations/persons involved in Autism carried out during the EYPD 2003 project (with the support of the European Commission, DG EMPL.), and the reflections on the quality of residential facilities carried out during the partnership in the project "Included in Society (with the support of the European Commission, DG EMPL.), a debate has been developed across the Autism Europe membership on the need and possibility to promote a European Accreditation System for service delivery for Autism.

Autism is a chronic developmental disorder, ranking from severe to moderate, which results inevitably in a significant lifelong disability.. **Autism is different from all other disabilities**, and its particular features and learning style require very specific intervention. Moreover **autism is a lifelong condition**. This means that persons with autism need lifelong protection at different levels of help, lifelong continuity of services and opportunities for living an independent adult life outside their families. No person with autism should be deprived of the freedom to develop his or her own way of life in as independent a way as possible. The development of their unique potential, as well as their quality of life, depends more on the availability of suitable, proper, lifelong facilities than on the degree of individual impairment.

Services must support the development of the person from early childhood and their social inclusion in the community by providing special education programmes as early as possible, lifelong training in functional areas such as communication and behaviour, social,

work and leisure skills, personal autonomy, and all the support needed for an independent adult life in the community and outside their families. Confronted by an uncertain future, the fears of their families could be dispelled by early planning in how to take care of the child on a daily basis and for the rest of her/his life and depending upon the evolution of the child. The prospect of a dignified future for the child in community-based residential services also provides the most effective emotional support for parents.

This obviously calls for a political program for autism, to create facilities and continuous lifelong services that are specific, rigorous, flexible yet consistent. This means also that Quality of the services is not a secondary issue in advocacy activities for persons with autism. The availability, reliability and quality of the support services can make the difference between a dignified, worthwhile life and an useless lifelong dependency.

Like any other human being, a person with ASD wants to live a full, worthwhile life within their unique possibilities, to benefit from opportunities to achieve independence and a good quality of life in terms of physical, emotional, social and material well being and freedom from abuse or exploitation.

In order to achieve their own potential and a meaningful, self-determined life as independently as possible in due respect of human rights and individual freedom, persons with autism need consistent long-term, specific support.



Such support has to be provided by means of qualified, reliable yet flexible services, organized in a professional way, providing not only persistence and stability but also an environment that fosters communication and is adapted to their behaviour and social interaction problems. Families must have permanent contacts and dialogue with the staff, the opportunity to express their needs, priorities and hopes and to participate fully in the development, monitoring and review of individual plans.

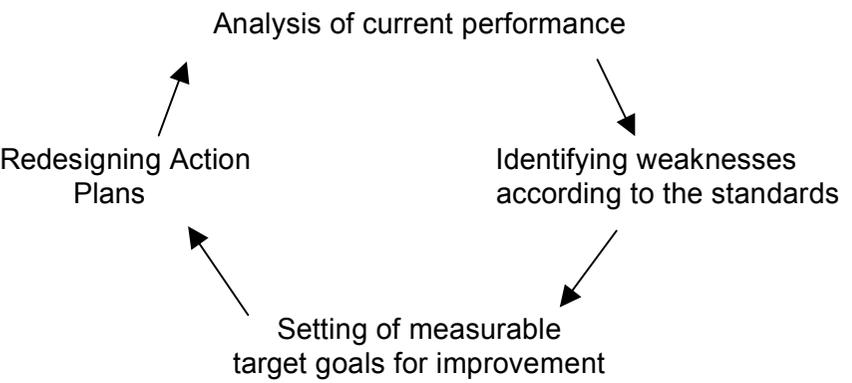
In order to achieve these goals, services should provide specific, qualified intervention consequent to current, updated knowledge as well as a stable and reliable structure that adopts quality standards related to the quality of life of the users and is based on a set of rules defining responsibilities, day-to-day routines and procedures.

A round table was organised on 1st October 2004 in order to share the expertise of our organisation members across Europe on Quality Assessment Programmes for Autism and promote discussion on the possibility to set up common quality criteria. The most significant, well documented experiences in this field were presented by the National Autistic Society (UK) and Gautena (Basque region, Spain), while other organisation members provided very useful documents on their Quality Control Systems. The discussion that subsequently developed among the members of Autism Europe led to the production of the present document.

All the quality systems adopted by our members share the principles described above, while adopting slightly different methods of quality control. Here below is a synthesis of the main features of the Quality Assessment approaches adopted by our organisation members.

APPROACHES TO QUALITY FOR AUTISM SERVICE DELIVERY

MAIN FEATURES

QUALITY ASSURANCE SYSTEMS (ISO - International Standards Organisation)	TOTAL QUALITY MANAGEMENT
Standard-based system to promote the exchange of goods and services across nations.	Participatory evidence based form of quality review
Cyclical process to achieve outputs and target setting  <pre> graph TD A[Analysis of current performance] --> B[Identifying weaknesses according to the standards] B --> C[Setting of measurable target goals for improvement] C --> D[Redesigning Action Plans] D --> A </pre>	Continuous process to achieve ever-improved performance Quality outcome areas identified by all the stakeholders. Setting up the Evaluation Team ↓ Every assessor team member reviews a user's programme against the quality outcomes areas ↓ Review of the success of the service in meeting the individual needs according to the outcome areas ↓ Producing an action plan to address the identified quality issues ↓ Public commitment by the service to the action plan
Conformance to an external set of performance standards	Conformance with the requirements of users
Aimed to achieve international performance standards	Aimed to achieve a unique Quality Framework
Aimed to keep errors within limits	Aimed at excellence, accepting zero level errors
Quality standards related to the organisation's management	Quality directly related to the outcomes for users
Based on external audit of the management against standards	Based on preventing errors
Quality evaluation made by external assessors	Quality evaluation made by a review team involving service staff, users and other stakeholders
Quality measurement in terms of indices or process indicators	Quality measurement in terms of real costs of doing things wrong
Under the manager's or special quality section's responsibility	Under the personal responsibility of every stakeholder

APPROACHES TO QUALITY FOR AUTISM SERVICE DELIVERY

MAIN STRENGTHS...

QUALITY ASSURANCE SYSTEMS (ISO - International Standards Organisation)	TOTAL QUALITY MANAGEMENT
Objectivity	Client-oriented
Comparable measures	Flexible and responsive to new challenges
Get the staff used to analysing, planning and documenting procedures and activities	Gets the staff used to self-evaluation
Homogeneous documentation	Improves the feeling of active participation
Improves co-ordination and communication across services	Improves personal responsibility
Coherence of information and rules	Not very expensive, accessible to small organisations

... AND WEAKNESSES

QUALITY ASSURANCE SYSTEMS (ISO - International Standards Organisation)	TOTAL QUALITY MANAGEMENT
Expensive and time consuming	Subjectivity
Rigid in putting barriers in the way of change	Limited assessment of system and procedures
Unresponsive to new demands	Misinterpretation of outcomes



CONCLUSIONS

The Accreditation Systems adopted by the Autism Europe's organisation members present the main elements of both the Quality approaches summarised above (QUALITY ASSURANCE SYSTEMS ISO and TOTAL QUALITY MANAGEMENT). The Accreditation systems adopted by the Spanish organisations (Gautena, Autismo Burgos) seem to be inspired mainly to the ISO system, completed by elements of the TQM system in order to achieve client oriented service delivery, while those adopted by the U.K. organisations (NAS, Autism Initiatives) seem to privilege the TQM system, improved by elements of the quality assurance system aimed to enhance the standardisation and reliability of the quality measures.

However, in some EU countries/regions (Spain, Italy), the ISO certification for health /social services is compulsory, is based on external standards set up at an international level and requires an external audit carried out by a specialised organisation. As a consequence, it is not accessible to European advocacy networks such as Autism Europe.

On the contrary, a European network putting together the expertise of many organisations from different countries and cultures could have a fundamental role in a TQM international system by:

- collecting as wide a range as possible of users' requirements
- promoting consensus meetings to identify a common setting of quality outcome areas
- promoting full awareness of the human and social rights of persons with autism
- defining a model for user programme reviews
- promoting the adoption of standardised tests to assess user satisfaction
- defining training modules for staff and users
- promoting the collaboration of Research Centres and Universities with expertise in the field of Quality services and autism at an international level to support the quality review process at all levels

Autism Europe thanks all its members for their participation in the discussion and in particular the associations that presented a detailed report:

- National Autistic Society
- Gautena
- Autisme France
- Autism Initiatives
- Autismo Burgos

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