Autisme – Europe

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AUTISM-EUROPE DOCUMENT ON QUALITY OF SERVICES FOR PERSONS WITH ASD

With the contribution of the members of the Council of Administration of Autism Europe

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BACKGROUND

1. The European context

1.A The European Union

The issue of the quality of services for persons with disabilities is high in the EU agenda. In April 2006 the **EU Commission** adopted a **Communication on Social Services of General Interest** [1], taking the specific nature of social services into account at European level and clarifying, to the extent that they are covered, the Community rules applicable to them.

Furthermore, the **European Disability Action Plan 2006-2007**[2] has established as a priority to promote access to quality support and care services, considering that: " *promoting quality, affordable and accessible social services and support to disabled people through consolidated social protection and inclusion provisions will be at the core of EU mainstreaming actions… Quality aspects of disability-related social services will also be explored, including the need to promote coordinated delivery of services*".

In this context, a thematic dialogue on SSGI to people with disabilities has been engaged by the **Disability High Level Group**, made up of representatives of all the Members States under the Commission presidency, in order to explore in particular how relevant quality aspects of disability-related social services can be taken into account, including the need to coordinate the delivery of services.

To this aim, the Disability High Level Group, has drawn up, with the collaboration of organisations representing people with disabilities, providers of services to people with disabilities and stakeholders in the field, a document on the "**Quality of the Social Services of General Interest (SSGI) from the viewpoint of disability**". This document has been largely inspired by the AE document on the Quality of services for persons with ASD (2005). Its purpose is to provide guidance and inspiration on how to promote quality social services addressing the particular needs of people with disabilities. It is addressed in particular to actors active in the areas of social protection and social inclusion, including the Member States.

This paper is also to be considered in the context of the **European Social Fund programming for 2007-2013**, which includes a priority on reinforcing social inclusion of people at disadvantage, including people with disabilities. The considerations in this paper follow the principle of mainstreaming, which can be defined as the systematic consideration of the specific needs of people with disabilities when designing social inclusion and social protection policies.

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[1] Communication from the European Commission "Implementing the Community Lisbon Programme: Social Services of General Interest in the European Union COM(2006)177 final 26.04.2006

[2] Communication from the European Commission on the situation of disabled people in the enlarged European Union COM (20005) 604 final 28.11.2005

1.B The Council of Europe

In 2006, the Committee of Ministers of the **Council of Europe** issued "Recommendations to member states on its Action Plan on disability to promote the rights and full participation of people with disabilities in society"[3]**.** The Council of Europe **Disability Action Plan 2006-2015** is a plan that commits Member States to take action to ensure respect of human rights of disabled people across all areas of life. It seeks to translate the aims of the Council of Europe with regard to human rights, non-discrimination, equal opportunities, full citizenship and participation of people with disabilities into a European policy framework on disability.

The CoE Action Plan for Disability considers "*essential that all policies, services and actions be underpinned by high quality standards… People with disabilities should be the focal point of the services provided. Client satisfaction should be the primary motivation for viable quality policies. It is vitally important that people with disabilities, the service users, should be active participants in quality assurance and monitoring of services.*

Training is also an essential element of quality service. This not only includes appropriate training for the personnel involved in service delivery, both disability specific and mainstream services, but also for those who have a role in developing policies which affect the lives of people with disabilities. Training should incorporate awareness of the human rights of people with disabilities".

2. The particular challenges in designing quality services for persons with ASD

ASD are developmental disorders ranking from severe to moderate, which inevitably result in a significant lifelong disability. This means that persons with ASD need early, lifelong, qualified intervention, lifelong protection at different levels of help, lifelong continuity of services and opportunities for inclusion in the community . The development of their unique potential, as well as their quality of life, depend more on the availability of suitable, proper, qualified 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 as independent as possible 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.

[3] Recommendation Rec(2006)5, adopted by the Committee of Ministers on 5 April 2006.

This obviously calls for **continuous lifelong services that are specific, rigorous, flexible yet consistent**. This means also that **Quality of the services is not a secondary issue in ensuring the full enjoyment of human and fundamental rights to persons with autism**. The availability, reliability and quality of the support services can make the difference between a dignified, significant life and dependency.

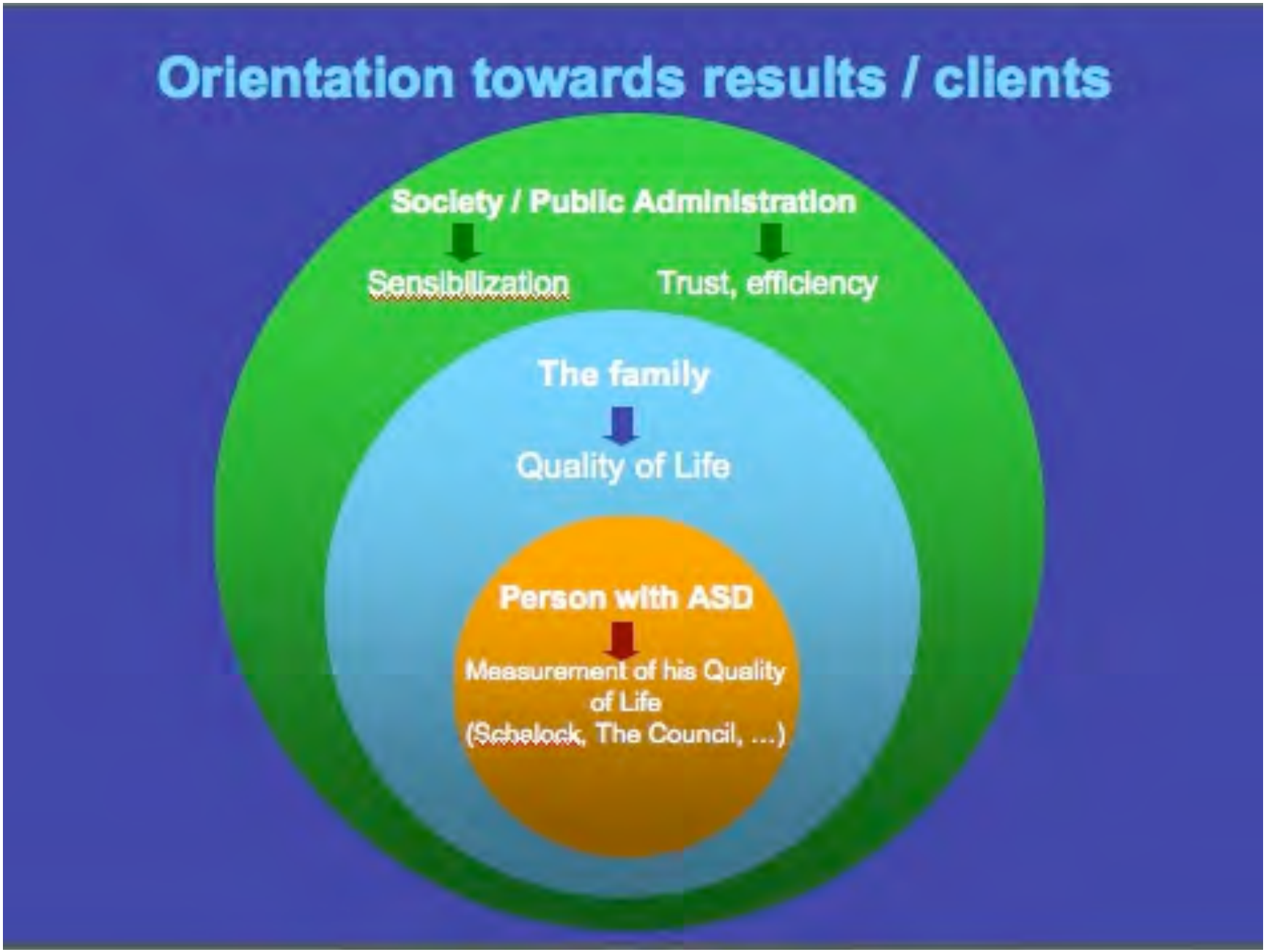
Like any other human being, a person with ASD wants to live a full, worthwhile life within their unique possibilities, to benefit from opportunities to achieve independence and a good quality of life in terms of physical, emotional, social and material well being and freedom from abuse or exploitation.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

Such support has to be provided by ensuring:

- Available qualified services organized in a professional way, providing
- persistence and stability of care, as well as
- specific intervention strategies, which are consequent to current, updated knowledge, to meet the specific needs ,
- flexible intervention programmes, to meet the individual needs of each user,
- an environment that fosters communication and is adapted to prevent and minimize challenging behaviours,
- ongoing dialogue with families to meet their needs and priorities in the respect of the best interest of the person with ASD,
- active participation of the families in the development, monitoring and review of individual plans.

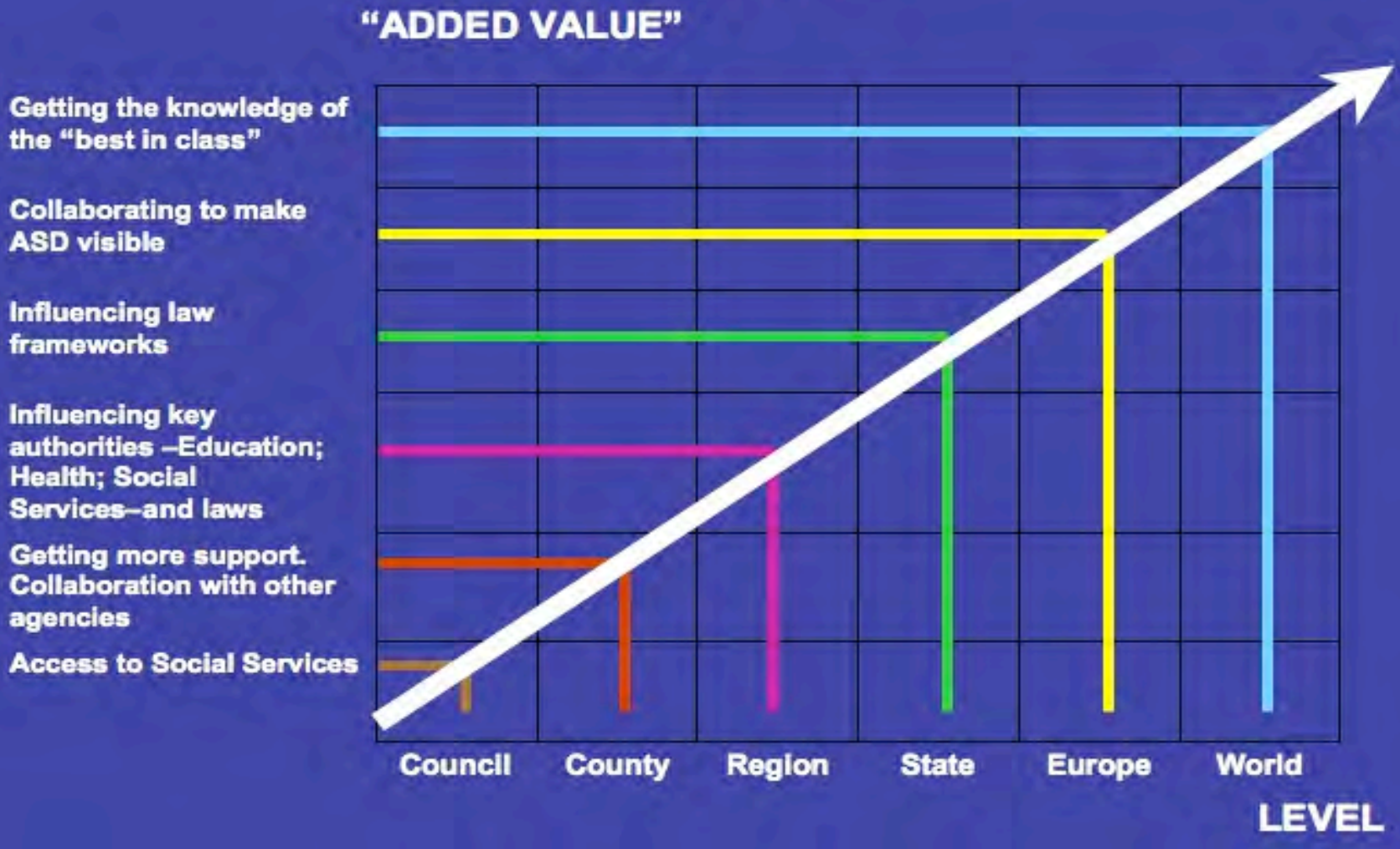
In order to achieve these goals, services should provide specific, qualified intervention in stable and reliable structures that adopt :

- quality standards related to the outcomes, in terms of enjoyment of human rights and quality of life of the users,
- a set of rules defining responsibilities, day-to-day routines and procedures.
- participation of users and their representatives at all stages of the process


Orientation towards results / clients
Society / Public Administration
Sensibilization
Trust, efficiency
The family
Quality of Life
Person with ASD
Measurement of his Quality of Life
(Schelock, The Council, …)

Leadership
Technical Leadership
Families Leadership
GOOD BALANCE
Managerial Leadership

Alliances


"ADDED VALUE"
Getting the knowledge of the "best in class"
Collaborating to make ASD visible
Influencing law frameworks
Influencing key authorities –Education; Health; Social Services–and laws
Getting more support. Collaboration with other agencies
Access to Social Services
Council
County
Region
State
Europe
World
LEVEL

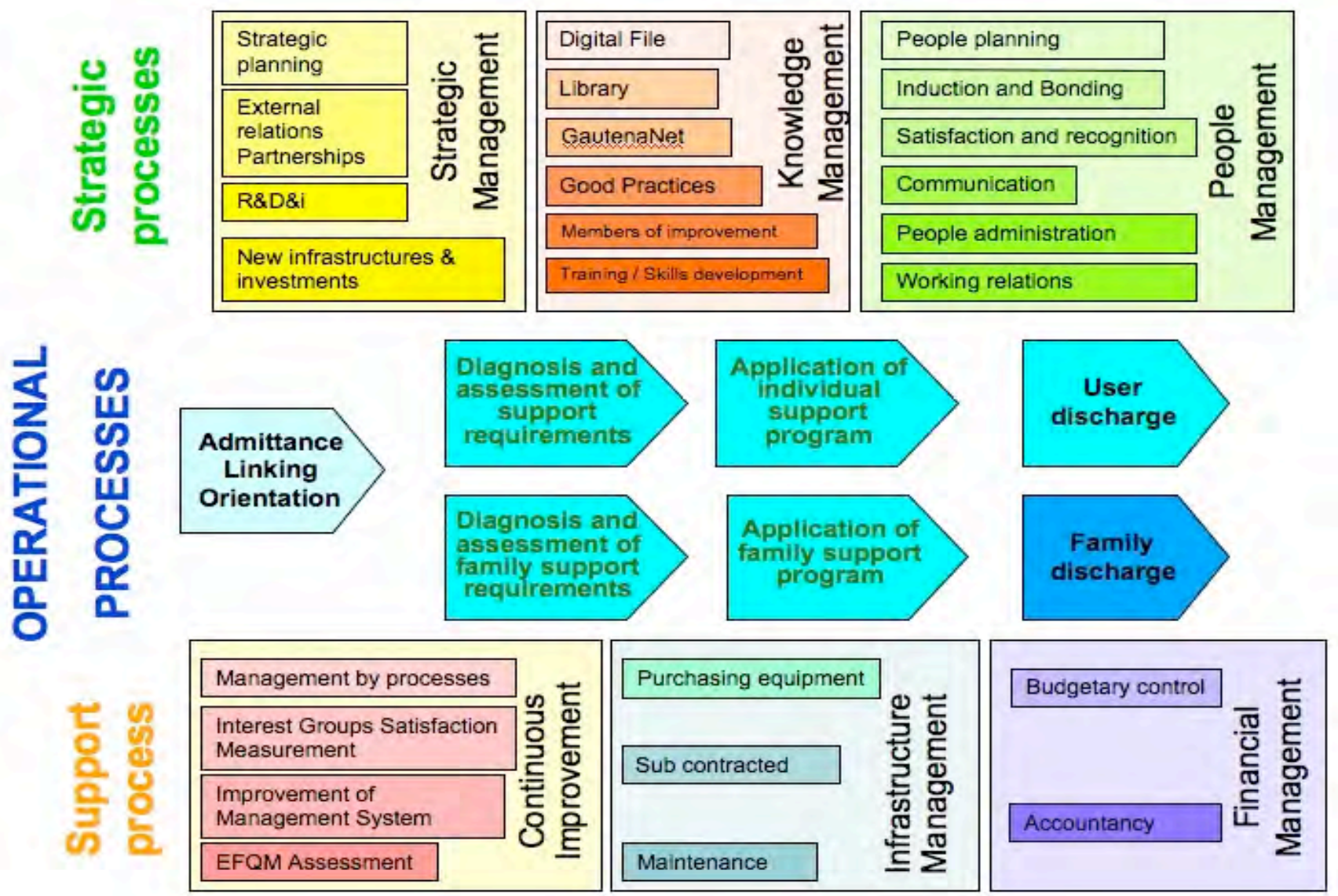
KEY GOALS	*KEY FEATURES*	*QUALITY CRITERIA*	*QUALITY INDICATORS*
1. What are the pre-conditions to be put in place by the social/health/education systems to ensure the rights of users with ASD can be exercised in practice?	**A. Availability**	Provisions and services specifically designed for ASD	Proportion of habilitation and education facilities and support services (compared to the expected rate of persons with ASD) Proportion of residential services and sheltered units specifically designed for adults with ASD
		Range of educational provisions and services for ASD	Proportion of education facilities for children and adults with ASD • special schools specifically designed for children or adults with ASD included in the education system • special classes specifically designed for children or adults with ASD included in the in the mainstream schools • ordinary educational establishments with provisions for students with ASD • students with ASD included in the mainstream school with qualified support
	B. Accessibility	Proximity of the services	N° of persons with ASD living in their community of origin
		Transparency of the waiting lists	Rules defining the criteria for admission
		Adapted transport	Ad hoc transport services Qualified assistance for transfers
	C. Affordability	No or minimal financial contribution requested to the users	Financial contribution (if requested) calculated on the basis of the user's income (not the family's income) Financial contribution (if requested) calculated on the basis of the evaluation of the needs

KEY GOALS	*KEY FEATURES*	*QUALITY CRITERIA*	*QUALITY INDICATORS*
	D. Persistence of the care	Range of provisions and services for all ages	Proportion of facilities and services for pre-school. children, school aged children, adolescents and adults, including sheltered housing units adapted to the needs of persons with ASD
		Coordinated and consequent delivery of services at all stages in a life-cycle approach	Agreements between Health, Social and Education authorities at national and local level Counselling and support for the transition Timely planning of the transition at individual level Case manager
		Good governance	Rules defining responsibilities, day-to-day routines and procedures Card of the service freely available Transparency and accountability of the financial management Regular external audits
2. What are re the conditions to be put in place to ensure the needs of users with ASD are met?	**E. Addressing general needs**	Effective and ongoing functional habilitation, education and vocational training programmes	N° of persons with ASD • in the open job market (with/without support) • in sheltered workshops • living independently
		Inclusion in the community	N° of persons with ASD in the mainstream school Facilities located within the community Small groups of users in the specialised facilities Frequency of contacts with peers N° of users participating in leisure/sport activities in the mainstream on a regular basis Support to families
		Free choice	Availability of updated lists of suitable services Availability of updated cards of the provided services

	KEY FEATURES	*QUALITY CRITERIA*	*QUALITY INDICATORS*
		Ongoing follow-up of the general health conditions	Health professionals in the service General health prevention programmes Qualified staff for accompanying persons with ASD in the general or specialised health facilities
	F. Addressing ASD specific needs	Reliable detection and diagnosis	Adoption of internationally accredited instruments for detection and diagnosis
		Qualified staff	Qualification and expertise of the recruited staff in the field of ASD
		Trained staff	Structured training opportunities in the field of ASD Annual training programmes concerted with the direction of the service
		Performant staff	Regular measurement of staff satisfaction Evaluation of the burn-out rate of the staff
		Evidence-based approach	Adoption of intervention strategies based on a sound scientific culture and updated knowledge in the field of ASD (behavioural / cognitive-behavioural strategies)
		Functional intervention	Intervention aimed at developing, improving and maintaining: • Social skills • Communication skills • Adaptive behaviour • Personal autonomy • Work skills • Leisure skills
		Choice	Users involved in decision concerning them Use of alternative-augmentative communication tools

	KEY FEATURES	*QUALITY CRITERIA*	*QUALITY INDICATORS*
		Prevention and treatment of challenging behaviour	Use of alternative/augmentative communication modes and methods Use of sound behavioural strategies Adaptation of the settings
	G. Addressing individual needs	Individually tailored programmes	Adoption of reliable instruments for individual assessment of capacities, potential and impairments
		Positive approach	Individual programmes consequent to individual preferences, motivation and aptitudes
		Choice	Use of individually tailored alternative-augmentative communication tools Individually tailored programmes to develop capacity of choice
		Functional individual programmes	Concrete, measurable objectives identified in the individual programmes Objectives of the individual programme consequent to: • developmental age • chronological age • priorities of the family • environmental resources
		Flexible individual programmes	Frequency of individual re-assessment of • achieved objectives • developed skills Frequency of adjustments of the individual programme on the basis of the individual re-assessment
		Ongoing assessment of outcomes	Regular administration to users of standardised checklists to evaluate quality of life Regular administration to user and their families of standardised checklists to measure satisfaction Ongoing assessment of challenging behaviour

KEY GOALS	*KEY FEATURES*	*QUALITY CRITERIA*	*QUALITY INDICATORS*
	G. Addressing individual needs	Correct use of medications	Informed consent of the concerned person or of its legal representatives when needed
3. What are the conditions to be put in place to ensure the participation of the users with ASD and/or their families and representatives can be exercised in practice?	**H. Active involvement of users and their representatives**	Active involvement the families in the diagnosis, assessment and care	Timely communication of the diagnosis Written information on the features of autism Reliable checklists for the assessment of the individual development administered to families as part of the individual assessment Detailed written report of the individual assessment timely provided to families Parent priorities and advice collected to draft the individual programmes Availability of parent training programmes Parent training aimed to enable parents to deal with the challenging behaviours
		Empowerment of families	Written information to families on the rights of their child Contact with representative parent associations
		Involvement of families in the service management	Assessment of the user satisfaction by means of standardised checklists Involvement of representative parent association in the assessment of the quality of the service


Strategic processes
Strategic planning
External relations Partnerships
R&D&i
New infrastructures & investments
Strategic Management
Digital File
Library
GautenaNet
Good Practices
Members of improvement
Training / Skills development
Knowledge Management
People planning
Induction and Bonding
Satisfaction and recognition
Communication
People administration
Working relations
People Management
OPERATIONAL PROCESSES
Admittance Linking Orientation
Diagnosis and assessment of support requirements
Application of individual support program
User discharge
Diagnosis and assessment of family support requirements
Application of family support program
Family discharge
Support process
Management by processes
Interest Groups Satisfaction Measurement
Improvement of Management System
EFQM Assessment
Continuous Improvement
Purchasing equipment
Sub contracted
Maintenance
Infrastructure Management
Budgetary control
Accountancy
Financial Management