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Module 3: Basic Principles and Strategies of Intervention

IPA+

Autism- training for inclusion



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The role of family and/or carers:

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The changing role of families through the different life stages of the person with autism

From the conceptual shift when the psychogenic theories from the 40s excluded parents from their children education to the growing body of knowledge that recognised **parents/families** as the essential treatment partners and the **primary decision makers for their children**

The growing empowerment of parents /families changed their role:

Parents feel “guilty for the autism of their child



Co-educator
Decision maker
Partner of the Professionals

The changing role of families through the different life stages of the person with autism

Partnership between families and professionals; different roles.

The role of the professional

- To define principles of collaboration with the families
- To consider the person with autism as a full rights member in the society
- To understand the role of the family in the development and education of the person with autism
- To know what to teach to the parents and to other members of families
- To know how to listen and to learn from families

The changing role of families through the different life stages of the person with autism

Relevant indicators on the relationship of the professional with the family: communication, confidence, effective training for families, respect, equity in decisions.

*(Revista Española sobre Discapacidad Intelectual
Vol 45 (2), Núm. 250, 2014, Pág. 19 a pág. 56)*

Parents and professionals are partners. Both want the same:
A better quality of life for the person with autism

(Schiltmans, C., Vermeulen, P, 2003)

In the perspective of professionals Dimension professional/family

Tabela 2. Indicators (items) of each one of the 3 dimensions of the questionnaire, ordered from the higher frequency to the lower frequency of the answer.

Dimension	Indicators	Frequency	Percentage %
Dimension 1 centred in the dimension professional/family	Comunication	46	79,3%
	Confidence	33	56,9%
	Efective training of families	26	44,8%
	Respect	21	36,2%
	Equity in the decisions	20	34,5%
	Orientation of the client	18	31,0%
	Confidentiality	15	25,9%
	Positive acceptance of the opinions, believes and values of the families	14	24,1%
	Accessibility and disponibility of the profissional	13	22,4%
	Compromise	11	19,0%
	Adaptation to the family language	9	15,5%
	Honesty	9	15,5%
	Other	5	8,6%
Dimension 2 centred in the dimensión professional/ person with PEA	Attention to the individual needs	55	94,8%
	Good competencies in the support of persons with PEA	47	81,0%
	Centred in the positive aspects and strenghts	44	75,9%
	To defend the rights of the person	33	56,9%
	To keep the security of persons	20	34,5%
Dimension 3 centred in the personal profile of the professional	Other	12	20,7%
	Empathy	40	69,0%
	Professional and technical skills	36	62,1%
	Flexibility	30	51,7%
	Team work and cooperation	28	48,3%
	Tolerance to stress and self control	23	39,7%
	Initiative and creativity	20	34,5%
	Capacity to recognize, motivate and animate	18	31,0%
	Capacity to plan	10	17,2%
	Coherence	9	15,5%
	Other people development	8	13,8%
	Persuasion and influence	3	5,2%
	Group leader	3	5,2%
Other	2	3,5%	

Pozo, P. et al. (2014). **Estudio sobre las relaciones de colaboración entre profesionales y familias de personas con trastorno del espectro del autismo (TEA): la perspectiva de los profesionales**
Siglo Cero. 45(2)250.19-56

Balance between love, stimulation, support, education

The study carried out by IACAPAP that we presented in the last slide is a valuable document to illustrate a good partnership as understood by the professionals. The more voted item in the questionnaire was communication and next, confidence, following **training for parents**.

Professionals are aware of the need for training the parents

We take for granted that parents love their children but **love is not enough**. Parents must **learn** with professionals:

- **Early stimulation** to the baby
- Seek **support** in the family and in the community
- **Training skills for independent life and lifelong education**

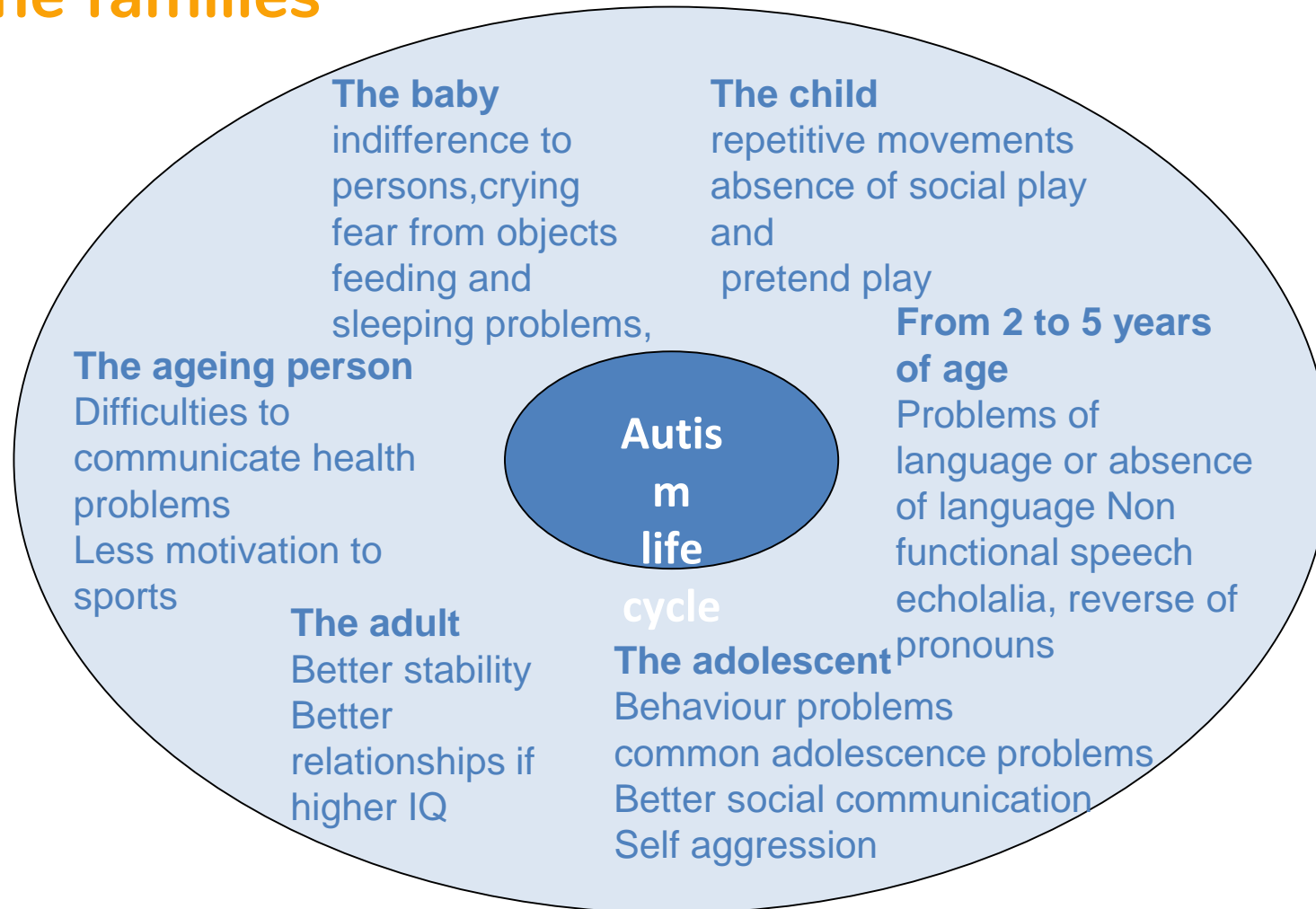
Balance between love, stimulation, support, education

- Individually tailored training programmes should also be available for families in order to improve quality of life
- Training should not be just a simple list of procedures but guidance in the evaluation of the situations and identification of the best solution to tackle them
- Parent training should help parents to better understand and meet the needs of their child with autism
- Families and professionals can work together and share their knowledge during training programmes
- Parents can also need training to deal with their children's difficulties and to improve the family life
- Professionals should provide parents with support and information on rights of the child and available services

Autisme Europe

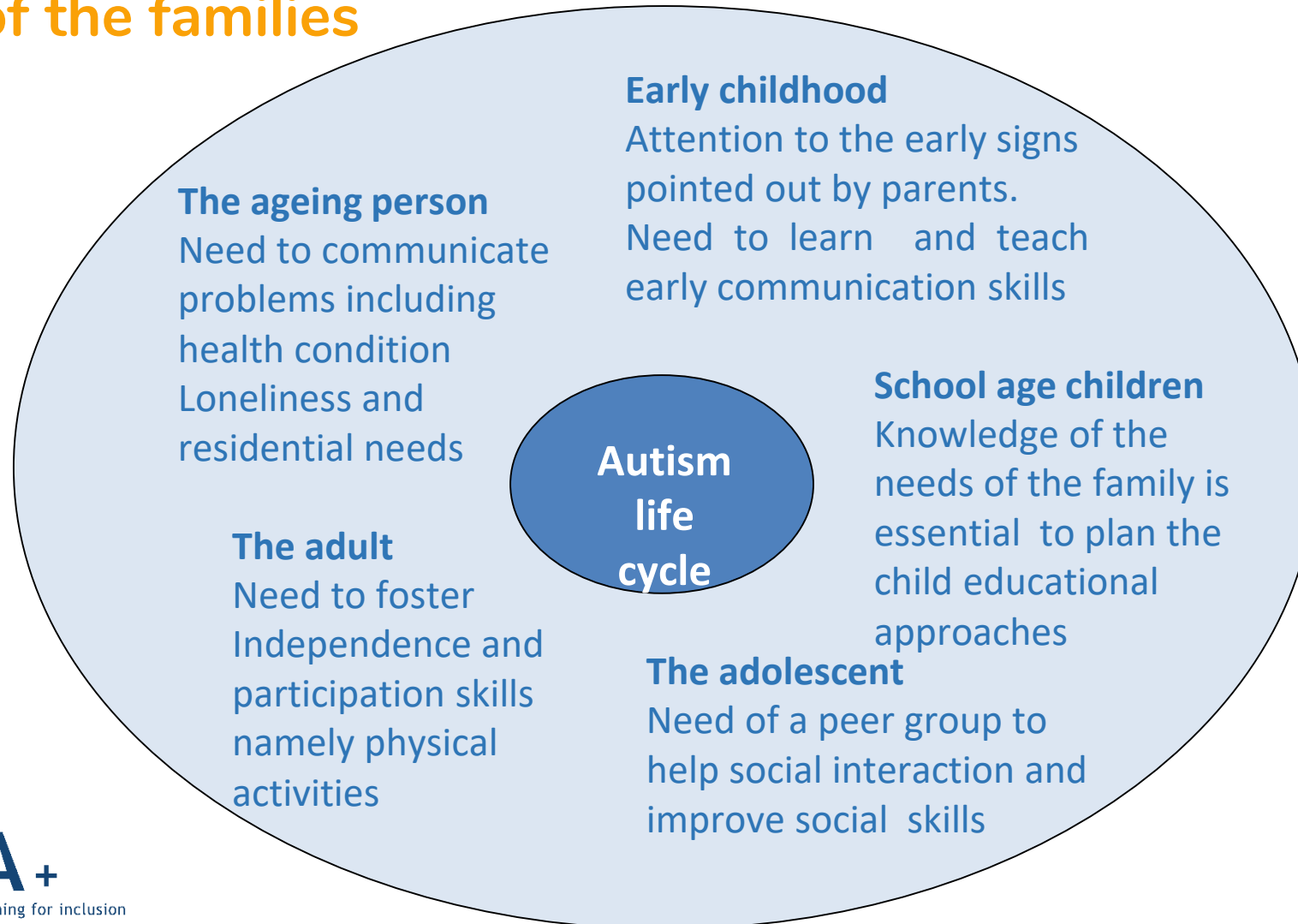
Characteristics of persons with Autism throughout their life cycle

Needs of the families



Dealing with persons with Autism throughout their life cycle

Needs of the families



**QUALITY OF LIFE -
the focal point at all
ages**

Needs of the Family – The baby

The Baby		
Characteristics	Needs of the family	Role of the family
Indifference to persons fear from objects feeding and sleeping problems, crying Poor eye contact Reduced responsive smiling Diminished babbling Reduced social responsiveness	Need to learn and teach early communication skills Need to understand the lack of social interaction Need of a proper diagnosis Child Development Clinic, Paediatrician, psychologist Before diagnosis – anxiety, interrogation Coping with diagnosis	Attention to the early signs pointed out by parents. They are the first to feel the difference, the first to detect early signs or strange behaviours Search for a professional help as soon as the first signs appear. Start diagnosis Learning to cope with the stress

Needs of the family – The Child

The Child		
Characteristics	Needs of the family	Role of the family
Impairment in the main areas of functioning: Communication Social interaction Repetitive movements Absence of social play and pretend play Non verbal Verbal with echolalia Good communication skills	Knowledge of the needs of the family=social, financial, marital, stress, frustration with the professionals knowledges Need to communicate with their children It is essential to plan the child educational approaches	Learning specific strategies with the professionals: alternative communication skills Training and education of parents Local parent support groups Family cohesion Learn effective coping skills Groups of siblings

Needs of the family –The Adolescent

The Adolescent		
Characteristics	Needs of the family	Role of the family
Behaviour problems Common adolescence problems Better social communication Self aggression Behaviour problems at school	Need of peer group to help social interaction and improve social skills problems related to adolescent + autism Learn how to deal with sexual activity The family must be involved in planning for the transition.	Promoting inclusive situation in the swimming pool, in the sport club, picnic, shows Preparation for a job Transition from school to active life or other service.

Needs of the family – The Adult

The Adult		
Characteristics	Needs of the family	Role of the family
Better stability	Need to foster	Join groups of parents
Better relationships if higher IQ	Independence and participation skills	Organizations
On the contrary problems of loneliness may appear	namely physical activities	Find solutions
Need of support	Need to find services for the future (residences, homes, etc)	Supported employment
		Voluntary work
		University
		Ask for new services new solutions

Needs of the Family – The Ageing Person

The Ageing Person		
Characteristics	Needs of the family	Role of the family
Difficulties to communicate health problems	Need to communicate problems including health condition	The family is no longer with the person. Parents disappear or are too old
Less motivation to sports, or to do outdoor activities, gardening,	Loneliness and residential needs	Prepare the future of the person without the family
	Changing places to live	Ask for services

Needs of the family – The Diagnosis

The diagnosis process –first contact with professionals.

- Parents need competence, empathy
- Parents need trust, communication, confidence from the professionals
- Parents need to be heard, to speak about their child. They need answers
- Professionals need to show competence and confidence
- Some parents refuse to accept the diagnosis process and the answers

After diagnosis - partnership with the doctors, nurses and/or other professionals.

- Report of the diagnosis and/or assessment according to the international classification criteria
- Clear report with a logic structure to help family or autistic person to understand it
- Easy reading version of the report

Needs of the family – The Diagnosis

During the diagnosis

- Professionals must be kind and show empathy to the family and the person with autism considering their emotional state during the process
- Elaborate, along the report, an assessment of the strengths and interests and specific needs required for the intervention
- Offer a useful working plan providing the family with an immediate route to follow in the future
- Avoid suppositions or future expectations about possible interventions that cannot be guaranteed from the services or in the environment
- Advice can be given but without false expectations or intervention and therapy that are not evidence based
- Facilitate information, training access, legal advisement, rights, obligations and the contact with other families

Needs of the family – The Diagnosis

The multidisciplinary team

Professionals implicated in the diagnosis and assessment:

- Make use of procedures and tools evidence based
- Must have specific, specialized and updated training
- There must be a good coordination among professionals
- Advice for families must be always available along the process
- All the professionals must transmit the same information along the process
- Information must be clear, avoiding ambiguous terms
- The privacy of information given by families must be guaranteed
- Orientation for families about entities and services for autistic persons may be given

Understable report with a logic structure to help family or person with autism to understand it

Needs of the family – The Diagnosis

Reactions to diagnosis differ from family to family

- All families need accurate information about autism and services available for the child
- Local parents support groups
- Access to parent training and education
- Education for carers and other professionals involved with the child

Stress and coping after results from diagnosis

- To deal with stress (*Harris, 1994*):
- Effective coping skills (parent training)
- A good social support network
- Family cohesion

Needs of the family

A comprehensive parent education programme will include:

- Information on autism
- Information and community support services available to the family
- Skill development to enhance parent-child, child-child, parent-parent and parent-professional interaction
- Information on rights, entitlements and public laws
- Strategies to help parents manage time, resources and competing needs
- Information on transition and future needs and service options for persons with autism

Needs of the Family

What is a practice centred in the family

- To conceive the family as a system of social support.
- To recognize the importance of the family's life context in the individual's development
- To focus on the strengths and resources of the families.
- To believe families can develop their strengths and increase their capacities.
- To invite members of families to go to meetings so they can share information.
- To involve members of families as active participants in every process of planning.
- To change the agenda of a meeting in order that any member of a family can share her/his concrete preoccupations.
- To empowerment families so they will be confident to act with efficacy in their own environment.

What is a practice not centred in the family

- To focus in the needs and weaknesses of persons and their families when planning interventions and services.
- To invite members of the family to meetings where they can bring information and make partnerships.
- To ask family members to tell their concerns and do not use the information to plan strategies.
- To ask families to choose among several options chosen by the professionals as the best for them.
- To ask members of families to carry on interventions those professionals identified as necessary and important for them.
- To assume that visiting families at home is the guaranty of a practice centred in the family.
- To become specialist in one or several concrete interventions and present them to every family in the same format.

The roles of the different members of the family and their empowerment

The 10 points to view the new way of thinking the role of families:

1. Children “grow best” in families

The opportunity to live in a family structure; enjoy a rich array of interaction and activity grounded in the family’s culture and beliefs

2. Family members are interdependent

They interact reciprocally and are mutually dependent

Professionals need to understand, appreciate and work with the entire family system to provide meaningful support

The roles of the different members of the family and their empowerment

3. Parents are the best judges of their children's needs

Parents, not professionals, know their children better than anyone else

They are in the best position to judge what services and supports are needed by the child.

Parents need to be supported in their efforts to secure needed services and supports

4. The family is the best long-term advocate for the child with autism

5. Families want involvement

Families want and need to be actively involved in all aspects of the child's educational programs.

Professionals must fully include families in the educational process and in all other services

The roles of the different members of the family and their empowerment

6. Professionals need to support families

Professionals need to consider all aspects of families to provide services and resources to strengthen the whole family

7. Parents should question professionals

Assertive parenting implies a questioning of professionals rather than meek compliance

8. Autism need not be negative

There is a growing body of evidence from parents, siblings and extended family members that the experience of autism can have profound, positive effects on the family as a whole

The roles of the different members of the family and their empowerment

9. Concern is for the long term

Although there are many real day-to-day concerns, the future and longer term are everyone's constant, underlying concern.

10. There is more than autism

Families are confronted by numerous issues in addition to those pertaining to the disability. Professionals need to recognize and affirm that other issues may need to be given priority by the family, and thus need to also be given priority by professionals.

Acting upon these 10 assumptions will empower and enhance the family

When professionals incorporate these assumptions into their clinical practice a true family/professional partnership can be developed and strengthened and families of persons with autism can be supported (Powell, T. et al.)

The roles of the different members of the family and their empowerment

The family as a system (*Turnbull & al, 1986*) serves as a good foundation for the understanding and examination of dynamics within the family of a child with autism.

Each family is unique and

each member contributes to the overall composition

influences all aspects of the family

is influenced by all other members of the family system

and by the system as a whole.

To meet the needs of family members with compassion and understanding, professionals must consider

dynamics of individual families, their needs, characteristics, strengths, values, resources and their particular stage in the family life cycle

The roles of the different members of the family and their empowerment

Turnbull and Turnbull (1986) consider 4 major components in the dynamics of a family:

Family resources – All individual members have personal characteristics that make them distinct from the others in the family system (abilities, capacities and resources) to meet the needs of which individual member and the family as a whole.

Family interaction – Focal point of the family system –those relationships related to the daily activities of the family and the cohesion among family members (closeness and distance among the family members)

Family functions – The needs that the family possesses that must be addressed. They may be economics/domestic/healthcare/recreation/socialization/self identity/affection and educational/vocational.

Family life cycle – These needs change across the family life cycle or developmental stages of each family

The roles of the different members of the family and their empowerment

Siblings interaction is in a continuous process of development that occurs throughout the life span

- Positive effects in the interaction between the children with autism and their brother or sister
- Reinforcement of the adequate behaviors
- Proposals of situations of social interaction
- Social relationships, in the family and with friends
- To help them to make friends in the regular school
- Teach him to live in a group of children

The unique needs of sibling

- Need for information about their brother or sister
- Need for respect for their own accomplishments
- Need for skills to assist their brother or sister
- Need to share feelings and experience with other people

The roles of the different members of the family and their empowerment

- **Siblings are an important part of the system**
- They initiate and receive social interactions
- They can be the support of their brother
- They are the models of their brother or sister with autism
- They are the teachers in methodology of peer teaching
- Even if they are not asked to do it, they feel responsible for their brother or sister
- They must live their lives. They must have time for themselves
- Parents must take care of the problems and concerns of the siblings towards the child with autism
- They must not ask too much from the siblings
- It is important that all members of families share responsibilities and tasks
- Each group of relatives has its function

The roles of the different members of the family and their empowerment

The siblings

- Problems and preoccupations of the siblings
- Services and future situation of his/ her brother and sister
- Their parents- time for them, their preoccupation, their feelings, their emotions, sadness
- Their own feelings towards their sister or brother with autism
- Their friends –how to explain the needs of his/her brother or sister with autism, how to accept the difference
- The school, the community – how to contribute to the inclusion of his relative

The roles of different members of the family and their empowerment

Support from extended family - Grandparents and other

- Grandparents play an important role to alleviate the stress of parents. Sometimes they are more patient than parents and well accepted by children with autism
- They support parents – they can assure the respite care
- Parents have difficulty in finding babysitters for their child with autism
- Members of the extended family like cousins, uncles, aunts, nieces can provide support in a variety of ways: besides company, they can offer occasional financial assistance or an opportunity to listen and reflect family members feelings

For professionals it is important to recognize the real and potential support that might be available through the extended family network. They can even assist the family in activating the support available through an extended family network

The roles of different members of the family and their empowerment – New families

Support to families – New strategies

Changing of the traditional roles of mothers and parents from the 60's

Mother was the main carer of the children. Father was working for keeping the economy of the family

The roles of father and mother are changing now:

Increasing numbers of mothers are working outside of their home. Fathers must share home activities and the care of the children.

Children with autism need much more attention. There is an exceptional burden for the couple

The professionals must discover and adapt new strategies to propose to the families
There is a need to refocus attention on strengths and capacities and the contributions of both parents as individuals and as a part of a whole family system.

The roles of different members of the family and their empowerment - New families

Support to extended family members

- Grandparents, cousins, uncles, aunts, nieces, nephews can be affected in one way or another by the presence of autism.They can be a major source of longitudinal and natural support to the immediate family. In the future they also be provided with necessary support

Support to Parents –Respite care. The community must provide the respite care for parents

Support to Single parents

- It is a more and more normal situation in our society to find a single parent household. Much more attention must be given to support strategies to help single parents with children with autism.

- Special attention must be given to the divorced parent who no longer lives with the child with autism.Their needs must be recognized and seek strategies to meet their needs

The roles of different members of the family and their empowerment- New families

Support to homosexual couples

Another reality in modern life it is a child with autism that lives with a homosexual couple. The strategies must be adjusted to that new situation: 2 mothers or 2 fathers

Support to rural families

There must be support services to children with autism and their parents that live in rural areas or far from towns and services

Support to families whose children cannot live at home

Support to children living in an institution

Finally there are more and more children to be living in an institution

New families – new strategies

The raising importance of the carer as a surrogate parent:

- Both parents work outside their home and grandparents are no longer available to take care of their grandchildren
- Children from unstructured families, recomposed families, divorced parents with different nationalities
- Migrants, refugees, victims of terrorism, children abandoned, orphans
- Children in institutions, in camps of refugees

New strategies

This new reality calls for urgent solutions from the communities:

Training for carers who are working in institutions with children with specific needs, namely autism

Training new carers to work with those children

Finding persons who want to be carers, searching for foster parents, for parents that lost their children in the migrations

Trying to search people from the same countries, the same religion

Involve the community in formal and informal support situations

Support from the community

Persons with autism, their families and carers need supporting from the community

Informal support: friends, neighbours, extended family members, church, community service organizations, involving people in the support to the population.

Formal supports and services: from the old institutional services to the Community services



Support from the community - new services

PHASES IN THE DEVELOPMENT OF SERVICES			
	INSTITUTIONAL	INTEGRATIVE	IN THE COMMUNITY
Who are they targeting?	Patient	User	Citizen
What is planned?	Caregiving	Developing skills	The future
Who makes the decisions?	Specialized professional	Multidisciplinary teamwork	The person with their circle of support
What are the principles?	Cleanliness, health and safety.	Skills and socialization	Self-determination, relationships and inclusion
What determines the quality?	Professional practice and level of care	Implementation of programs and objectives	THE INDIVIDUAL'S QUALITY OF LIFE

- From individual work to teamwork and collaboration networks
- From artificiality to functionality
- From technical intervention to empathy and personal relationship

Cultural differences

Supporting people with autism and their families or carers in the communities must take in consideration the new concept of citizenship.

The principles of self-determination, relationships and inclusion are central in this process

Persons with autism no longer will be considered the clients.

They have their own characteristics and preferences and their cultural environment (different religion, different ethnicities, different preferences) that must be respected.

The person with autism and their circle of friends or family are the decision makers

Inclusion in society

Inclusion in society does not mean abandon the person with autism and the family.

Education and care or any other provision must be given in inclusive settings among other persons.

A policy of inclusion should never be used to deny support or access to education and treatment to any individual with autism.

Inclusion in leisure activities and employment should be based on entitlement, not privilege, and should essentially assure that appropriate learning or other positive experiences take place in an environment as inclusive as possible.

(Autisme Europe, 2007)

Rights, empowerment, monitoring of the rights of autistic people

Autistic people have the same rights as any other citizens. It is important to be aware of some key concepts and topics:

- Social model of disability and Inclusion
- Role of support services
- Charter of rights of people with autism
- UN Convention on the Rights of People with Disabilities
- Empowerment of autistic people and the need to support adequately decision-making
- Importance of awareness awareness and understanding and fight stigmatisation

The medical vs the social model of disability



The medical model of disability

The **medical model of disability** views disability as a 'problem' that belongs to the disabled individual. It is not seen as an issue to concern anyone other than the individual affected.

For example, if a wheelchair using student is unable to get into a building because of some steps, the medical model would suggest that this is because of the wheelchair, rather than the steps.

This medical model approach is based on a belief that the difficulties associated with the disability should be borne wholly by the disabled person, and that the disabled person should make extra effort (perhaps in time and/or money) to ensure that they do not inconvenience anyone else.

The social model of disability

- The **social model of disability**, in contrast, would see the steps as the disabling barrier. This model draws on the idea that it is society that disables people, through designing everything to meet the needs of the majority of people who are not disabled. There is a recognition within the social model that there is a great deal that society can do to reduce, and ultimately remove, some of these disabling barriers, and that this task is the responsibility of society, rather than the disabled person.
- The **social model is more inclusive in approach**. Pro-active thought is given to how disabled people can participate in activities on an equal footing with non-disabled people. Certain adjustments are made, even where this involves time or money, to ensure that disabled people are not excluded.

Promoting inclusion in society

Inclusion in all areas of life is a basic element of human rights.

Do ensure inclusion, some people with autism need a high level of support, and thus require:

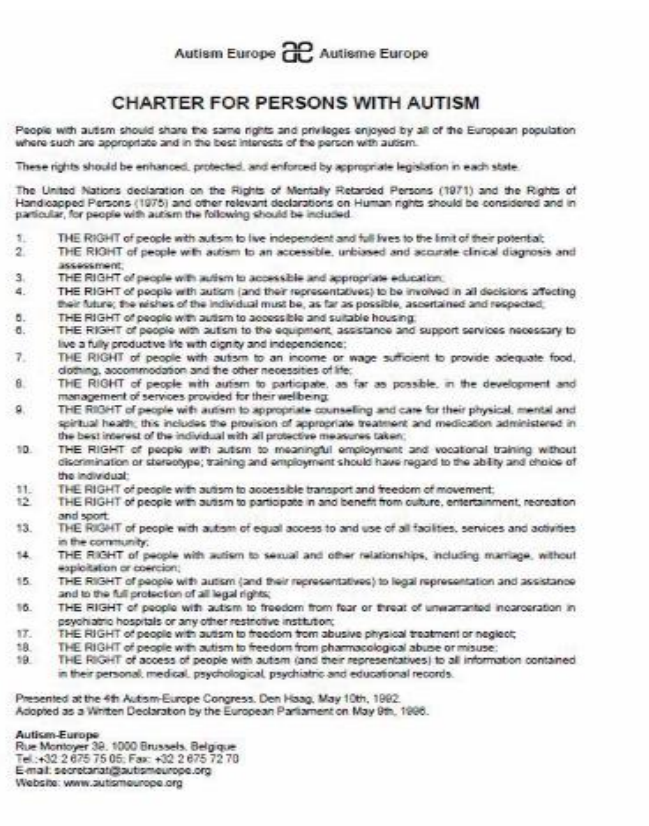
- **intensive and permanent quality services** geared to their specific needs
- **intensive planning and co-ordination** across relevant authorities, government agencies and service providers both at national and local levels

Their quality of life is very much dependent on the availability of appropriate and quality services that respond to their and their families' needs

(Coe Committee Of Ministers' Recommendation on Disability Action Plan 2006-2015)

A rights-based approach to autism: the charter of rights

In the 90s, Autism-Europe adopted a charter of rights for autistic people, it was an important step towards a right-based approach



A rights-based approach to disability: UN Convention on the Rights of People with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) entered into force in 2008.

It is a legally-binding instrument which has been widely ratified (by all EU Member States except Ireland, and by the EU as a regional organisation).

The CRPD is based on the human rights-based approach to disability, moving away from the medical model. This change is profound and is therefore often defined as a paradigm shift.

A rights-based approach to disability

At the heart of the rights-based approach to disability is the recognition that persons with disabilities **are active subjects with equal rights** and not merely people in need and passive recipients of aid. The UNCRPD addresses all areas of life.

It implies - Full inclusion and participation for all disabled persons throughout:

Legal instruments

Policies

Provisions and services

Equal Opportunities in all areas of life :

Education

Vocational training and employment

Health care (including proper diagnosis)

Habilitation, etc

UN Convention on the Rights of People with Disabilities

Guiding Principles

“States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability” (Article 4)

Empowerment of autistic people

Article 12 UNCRPD on legal capacity

1. States Parties reaffirm that persons with disabilities have the **right to recognition everywhere as persons before the law**.
2. States Parties shall recognize that **persons with disabilities enjoy legal capacity on an equal basis** with others in all aspects of life.
3. States Parties shall take **appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity**.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for **appropriate and effective safeguards** to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

Empowerment of autistic people

Article 12 UNCRPD on legal capacity

People with disabilities – autism in particular – might need support for exercising their legal capacity. To ensure the effectiveness of rights and the ability to exercise legal capacity, the UN Convention provides that people with disabilities have the right to receive support.

However, **maintaining the full legal capacity of an individual with a disability must always be at the centre** of the process when someone is supporting a person with a disability to make a decision or is delegated to make a decision on behalf of a person with a disability. Therefore, and in light of the UN Convention, due diligence must be applied in order to act in the best interests of the supported person.

Supported decision-making must always start from the **presumption of full and equal legal capacity** of people with disabilities, including those with severe and profound levels of disability.

Empowerment of autistic people

Supported decision-making

A higher level of support may be needed for some adults with autism and severe intellectual disabilities who are unable to evaluate the consequences and implications of some of their actions (or inactions). Even when an individual requires a high level of support is in most, or all, areas of life including support in decision-making, States must take appropriate measures to ensure that the legal capacity of the individual is nevertheless enjoyed on an equal basis with others.

Regarding people with autism, the support in exercising legal capacity must not only be based on a personal knowledge of the individual, but also on the **knowledge of alternative and augmentative communication methods**.

Empowerment of autistic people

Supported decision-making

Support people should be **selected by the individual with a disability or his/her family, whenever possible**. It might be an advantage if the support person has known the individual personally for a significant period of time. In any case, the person with a disability should have the possibility to build a relationship of trust with his/her support person.

There should also be the possibility to assign several support people to one individual, particularly for people with severe and profound intellectual disabilities where a group of support people who know the individual in different capacities may better match all the support needs of a person.

In order to avoid conflicts of interest between a person with autism and their supporter, support people should never be linked to a psychiatric facility, governmental authority or a service provider on whom the person with a disability is dependent for some other purpose (for example, housing, education or health services).

In case any conflict arises, and to ensure accountability of support people, administrative procedures that are easily accessible for the supported person and their family should exist or be established.

Empowerment of autistic people

Supported decision-making: appropriate safeguards

The UN Convention requires that **appropriate and effective safeguards be put in place to prevent exploitation and abuse in the exercise of legal capacity** by people with disabilities. This is particularly necessary for people with autism who need a high level of support in all areas of life and require such safeguards at all times.

The UN Convention adds that safeguards should be **proportional and tailored to the person's circumstances**. This means that safeguards must be higher for people with a more severe degree of disability or with high support needs, such as many people with autism. Safeguards must also be higher when major decisions regarding the life of the person are being made.

Safeguards might include: a procedure for careful assessment of the actual need for support, periodical re-examination of the support measures adopted and a mechanism for people with disabilities or their family members to make an appeal to change a decision that has been made. The safeguards must be separate from the support mechanisms, as they should protect the person with a disability from any exploitation or abuse by supporters.

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