AUTISM SPECTRUM DISORDER: PRINCIPLES AND PRACTICE

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Policlínica Gipuzkoa & Gautena Society
Donostia / San Sebastián, Spain
And, we also have Autism Spectrum Disorders....

In Gipuzkoa 0.5/100 children aged 7 – 9 (at least) present ASD

*Unpublished data (2018)*

So.... what do we do for them and why?
Autism Spectrum Disorders: Ten Tips to Support Me

Joaquin Fuentes, MD

The recently revised American Academy of Child and Adolescent Psychiatry Practice Parameter for the Assessment and Treatment of Children and Adolescents With Autism Spectrum Disorder highlights the importance of clinicians maintaining an active role in family and individual support. Its evidence-based recommendations coincide with those of the International Association for Child and Adolescent Psychiatry and Allied Professions, the European Society for Child and Adolescent Psychiatry, and Autism Europe. In contrast, in Europe, there is a greater emphasis on an approach to children and adolescents with autism spectrum disorder that is based on rights, participation, and quality. Inclusion Europe leads a campaign for making information easily understandable as an essential mechanism to foster citizen participation, ensure informed choice, and protect human rights.

Recognizing the complementary strengths in these approaches, my colleagues and I have produced a tool to empower stakeholders, guide caregivers, and provide a rationale for advocates. The document was originally produced by its author and then reviewed, edited, and formally endorsed by a self-help group of young persons with Asperger disorder and by the Board of Families from the Cipuzkua Autistic Society, the largest autism community program in southern Europe.

It is hoped that this document, also accessible in Basque, French, and Spanish, will become a framework for clinical practice and global advocacy.

AUTISM SPECTRUM DISORDERS: 10 TIPS TO SUPPORT ME

1. I am not “autistic.” I am first, foremost, and always a person, a student, a child, and I have autism. Do not confuse me with my condition. And, please, do not use the term in a negative or inconsiderate way. I deserve to be respected.

2. I am an individual. Having autism does not make me the same as other people with autism. Make an effort to know me as an individual, to understand my strengths, my weaknesses, and me. Ask me—and my friends and my family, if I cannot reply—about my dreams.

3. I deserve services, just like all children. Services for me begin early. Autism is—or it will be, when recognized—a public health issue in many countries of the world. There are instruments to screen it. They should be applied in the framework of screening for other developmental disabilities. If you start soon, my life will be different! And remember that about one quarter of my siblings will have autism or other problems. Help them; they are an important part of my life.

4. I belong in the health care system, just like all children. Include me in regular health care. The health care system should adapt to me, limiting waiting times and ensuring that I understand what is to be done, by using, for example, easy-to-read materials, pictograms, technological means, and so forth. Other patients also will benefit.

5. I belong with other children. Do not separate me from them because you want to treat me, educate me, or care for me. I can, and I should, be placed in regular schools and regular community settings, and special support should be provided to me in these places. I have something to teach other children and something to learn from them.

6. I belong with my family. Plan with me for my future and my transitions. I am the one who should decide, and, when my ability to do so is limited, my family and friends will speak for me. No government agency can take the...
I am not “autistic.” I am first, foremost, and always a person, a student, a child, and I have autism.

Do not confuse me with my condition.

And, please, do not use the term in a negative or inconsiderate way.

I deserve to be respected.
AUTISM SPECTRUM DISORDER

- Developmental Disorder (70 years ago)
- Early limitation in social, communication, sensory and play skills
- Origen: biological
- 50% associated intellectual difficulties & developmental challenges
- DIAGNOSIS: presence of characteristics + negative impact
- SIGNIFICANT INDIVIDUAL DIFFERENCES

- SUPPORTIVE ACTIONS

DIMINISH SYMPTOMS & REDUCE NEGATIVE IMPACT

Genetic counselling
New medications
Early intervention
Commorbidities tx

Educational programs
Social resouces
Environmental adaptation
Empowerment
I am an individual. Having autism does not make me the same as other people with autism. Make an effort to know me as an individual, to understand my strengths, my weaknesses, and me.

Ask me and my friends and my family, if I cannot reply, about my dreams.
Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 1).
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 1).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
Clasifications do not classify people

The support is not determined by the *grupal* characteristics of this population, but by the *specific* characteristics of each individual.

Use clinical instruments, and elaborate a shared report.
American Association of Intellectual and Developmental Disabilities

1. Communication
2. Self-help
3. Home living
4. Using the community
5. Self-direction
6. Health and security
7. Functional academics
8. Leisure and free time
9. Work
Who plays the music?
BENEFIT FROM MULTIPLE METHODS

Mix freely depending on needs, wishes and goals … and keep monitoring outcome!

HOW MANY HOURS?: ALL!
I deserve services, just like all children. Services for me begin early. Autism is or it will be, when recognized, a public health issue in many countries of the world. There are instruments to screen it. They should be applied in the framework of screening for other developmental disabilities. If you start soon, my life will be different!

And remember that about one quarter of my siblings will have autism or other problems. Help them; they are an important part of my life.
At risk population

DO NOT “SIT STILL”... SEARCH!

X-FRAG, Neurofibromatosis, Intelectual disability, Tuberous sclerosis

Older father and/or older maternal granfather when giving birth to the mother

No pholic acid before, during and after pregnancy

Valproic acide during pregnancy (Talidomide also...)

Siblings of children with ASD
FOLLOW-UP OF BABY-SIBS AT RISK IN CANADIAN STUDIES
L. Zwaigenbaum et al.

1. Specific markers at 12 months and **NOT** at 6 months
   Eye contact and gaze following.
   Orienting to name, smiling and social interaction, imitation, affect, early
cognition and reactivity

2. Passive temperament at 6 months, and exaggerated reactions by 12 months

3. Excessive visual attention to objects + decreased positive affect expression

4. Delay in receptive and expressive language by 12 months

   99 low-risk babies vs. 277 new sibs of ASD cases: **25% Dx+ at 36m of ASD**

46% OF THOSE DIAGNOSED AT 36 m. HAD NOT BEEN DIAGNOSED AT 24 m.!!
I belong in the health care system, just like all children. Include me in regular health care. The health care system should adapt to me, limiting waiting times and ensuring that I understand what is to be done, by using, for example, easy-to-read materials, pictograms, technologic means, and so forth. Other patients also will benefit.
PROTOCOLO DE ACTUACIÓN ANTE INTERVENCIÓN QUIRÚRGICA Y HOSPITALIZACIÓN PROLONGADA DE PERSONAS CON TRASTORNO DEL ESPERCTO AUTÍSTICO ASOCIADAS A GAUTENA.

REUNIDOS

De una parte D. Máximo Guillenches Fernández,
y de otra parte
D. Ramón Santillán Osábalde

El primero actúa en calidad de Director General del Hospital Donostia.

Y el segundo actúa en nombre y representación de GAUTENA, entidad que tiene el NIF 02002830 y su sede en la calle Francisco López Azpil 1 de Donostia-San Sebastián, como Director de dicha Asociación.

El acta se dirige a los pacientes a los que se dirigirá una mejor atención socio-sanitaria en el caso de una intervención quirúrgica, indicando las siguientes actuaciones:

1. Cuando se trate de una hospitalización quirúrgica se procederá en marco la prevenida el ingreso en el hospital. Un plan conjunto que implicará a todos los profesionales y también a las familias de los pacientes especialmente graves que puedan plantearse en este tipo de situaciones.
2. El Hospital Donostia como Institución prestadora de los Servicios Sanitarios designará un profesional médico de referencia en el caso de hospitalización prolongada de un paciente usuario de GAUTENA.
3. A efectos de ordenar adecuadamente la confusión de tratamiento ambulatorio y de ayudas de naturaleza social, se establece que el hospital designará a un Trabajador Social del Servicio de Admisión, para que coordiné y establezca con GAUTENA el plan específico de apoyo para la persona hospitalizada.
4. GAUTENA confía a su Director Médico como mediador en este ámbito, quien podrá facilitar la información de naturaleza médica, incluyendo la información procedente que el personal del hospital requiera para aclarar las condiciones de hospitalización, dato que puede ser de especial interés para el colectivo de personas que atendemos.
5. GAUTENA confía a una persona de su Equipo de Responsables que será el interlocutor de la persona que designe el Hospital como responsable de la supervisión del apoyo social, están acreditados, al dispositivo de apoyo que el paciente precisa.
6. Las familias de las personas con Trastorno del Espectro Autístico asociados a GAUTENA, se asignarán a la elaboración y a la estandarización de este protocolo de actuación sin perjuicio de las decisiones de su propio usuario y de los que corresponda a sus familiares directos.
7. A efectos de este protocolo se considerará hospitalización prolongada aquella que exceda de dos semanas.

Donostia-San Sebastián, a quince de Diciembre de dos mil tres.

Ramon Santillán
Director de GAUTENA

D. Máximo Guillenches
Director General Hospital Donostia

Osakidetza
| AÑO: | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 |
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| MARZO| ORT | MA | MF |
| ABRIL| |
| MAYO| |
| JUNIO| |
| JULIO| |
| AGOSTO| |
| SEPTIEMBRE| PS | MA | MF |
| OCTUBRE| VA | |
| NOVIEMBRE| H1n1 | |
| DICIEMBRE| |

**Indique la codificación utilizada:**
- MF: Médico de Familia
- A: Analítica
- P: Podóloga
- VA: Antigripal
- ORT: Ortopeda
- D: Dentista
- MARCAPASOS
- H1N1GRIPÉ A
- PS: Médico Psiquiatra

**AUTORÍA:**
- Cambio marcapasos 11 de Enero 2010
- D: pequeña caries pieza 27 y desvitalizar muela

Octubre 2010 Revisión Neurológica
I belong with other children.

Do not separate me from them because you want to treat me, educate me, or care for me. I can, and I should, be placed in regular schools and regular community settings, and special support should be provided to me in those places.

I have something to teach other children and something to learn from them.
Future age, life project and eco-functionality
12 “COMMANDMENTS” IN AUTISME

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<td>Profit from strengths</td>
<td>Empowerment</td>
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<td>Ecological functionality</td>
<td>Social skills</td>
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<td>Incidental Learning</td>
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<td>Task analysis</td>
<td>Control of the environment</td>
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<td>Environmental structure</td>
<td>Augmentative communication</td>
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Many platforms and software systems

Spanish, Basque, French, English – and bilingual

Real donated voices (C/A - M/F)

Very friendly for users
Over 83,000 downloads from 119 countries

www.fundacionorange.es
Video Tutorial de e-mintza

Una aplicación gratuita diseñada para diferentes soportes informáticos que genera un tablero de comunicación.

http://www.policlinicagipuzkoa.com/e-mintza.php
National Institute of Health Carlos III
International ASD Guidelines

And soon... another one!
Joaquín Fuentes  
Spain

Amaia Hervás  
Spain

Patricia Howlin  
United Kingdom

ESCAP PRACTICE GUIDANCE FOR ASD:  
A brief summary of evidence base recommendations for diagnosis and treatment  

(Vienna, June 2019)

+ Review by experts, Executive Board Endorsement + Open Access Publication in ECAP
I belong with my family. Plan with me for my future and my transitions.

I am the one who should decide, and, when my ability to do so is limited, my family and friends will speak for me.

No government agency can take the place of my family, and, please, make sure that our society values my family’s generosity when they support me on society’s behalf.
(2015 – 2018)

asdeu

Autism Spectrum Disorders in the European Union

14 COUNTRIES
Autism in Europe: 1%

1 + 3

Dementias

ASD

This is not the problem of a group of families but a public health problem.
I deserve the right to evidence-based services. These may not be convenient or easy, but when I get them, I do better.

Do not substitute my educational, health, and social support with medication. I may require medication, and I look forward to new developments in biological treatments, but you must be cautious in their use.

Count on me for research ventures; get me involved, with all my rights protected. I also want to help others.
PEOPLE ON PSYCHOTROPIC MEDICATION

Since 1998

<30%

56%

80%

Gautena

SINCE 1998
El Pharmautisme TR es un protocolo de tratamiento psicofarmacológico diseñado para su uso en población con discapacidad intelectual y/o del desarrollo. Su utilización, dentro de un sistema de aseguramiento de la calidad registrado por AENOR, ha permitido durante más de 10 años el que un programa comunitario comprensivo y multidisciplinar para el autismo en Gipuzkoa, País Vasco (España) consiga mantener menos del 30% de sus clientes en medicación psicotrópica; dato que se complementa con una alta satisfacción de sus usuarios y sus familias, y una cifra de institucionalización psiquiátrica de menos del 1%.

La garantía ética, el avance del conocimiento, la personalización para una óptima calidad de vida y la excelencia en la gestión constituyen los elementos esenciales en los que se integra la administración de psicofármacos en esta población.

Autores:
Joaquín Fuentes
Ignacio Gallano
Irna Isasa
Marivi Cundín
(Gautena y Policlinica Gipuzkoa)

Andrés Martin
(Yale Child Study Center.)

Potenciales conflictos de interés

Más información

WWW.PHARMAUTISME.ORG
ONGOING SATISFACTION EVALUATION

ISO-9001
Institutionalized care in long-term hospitals (35 y.)

< 0.1%
This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (IMI2 JU) under grant agreement No. 777394.

This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation program and the European Federation of Pharmaceutical Industries and Associations (EFPIA).
Who we are?

48 partners in 10 countries, 100-150 scientists
AIMS-2-TRIALS Consortium

132 million USD funding for development of research and clinical capabilities
I belong in society. Engage me in vocational training. I want to contribute.

The services I need during my adult life should be guided by self-determination, relationships, and inclusion in all the activities of my community.

Your goal must be to adapt the environment I have to face and modify settings and attitudes.

It also will make our society better.
“LIFE PROJECT”

My vision; our dream (myself + my L.A.R + others), that is modified according to my life cycle transitions...

A plan, possible and adequate, to give quality to my life...

PCP  Strategy to develop the ISP

A tool for reaching my

LIFE PROJECT
Personal vision and promotion of rights

Adaptive skills

Provision and coordination of supports for a life with quality

Outcomes in personal vision and promotion of rights

Outcomes in adaptive skills

Outcomes in Quality of Life

Annual evaluation of the intervention areas
Gipuzkoa County

5,950 employees (82% workers with disabilities)

Funding revenue:
Self-determination
Rights
Social inclusion
Interpersonal relations
Personal development
Material well-being
Emotional well-being
Physical well-being

I have human rights, and I face discrimination for many reasons.

Many of us live in poverty, with no community support system. Some of us are immigrants or minorities, including sexual minorities.

Keep a gender perspective. Girls and women with autism are often at greater risk of violence, injury, or abuse.
EMPOWERING CITIZENS WITH DISABILITIES IN HUMAN RIGHTS
COMBINATION OF DIVERSE WAYS TO SECURE HUMAN RIGHTS EMPOWERMENT

- 56% In a group
- 23% Individual
- 21% Represented
I belong in the world. I have a role to play.

We, and my legal representatives, want to be involved in policy making, its development, and its evaluation.

You need my help to know what should be done.

Empower me. **Remember my motto:**
Nothing about me

Without me
Material accessible on Internet in 42 languages

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Mary K. Billingsley, ELS

Autism Spectrum Disorders: Ten Tips to Support Me

Joaquin Fuentes, MD
Policlinica Gipuzkoa, San Sebastian, Spain

In the top 5% of all research outputs scored by Altmetric

One of the highest-scoring outputs from this source (#9 of 1,415)

High Attention Score compared to outputs of the same age (99th percentile)

High Attention Score compared to outputs of the same age and source (93rd percentile)
Autism Spectrum Disorders: Ten Tips to Support Me ...
www.jaacap.com/article/S0890-5/abstract Traducir esta página
de J Fuentes - 2014 - Artículos relacionados
Autism Spectrum Disorders: Ten Tips to Support Me ... Disclosure: Dr. Fuentes has received research support, has served as unrestricted speaker for, or has ...

Autism Spectrum Disorder: Ten Tips Guidance Article
www.elsevier.com/.../autism-spectrum-disorder-ten-t... Traducir esta página
4 nov. 2014 - Dr. Fuentes said of his article, "We see in our nations a radical evolution ...
... The article "Autism Spectrum Disorders: Ten Tips to Support Me" by ...

Ten Tips to Support Me | Autism Speaks
https://www.autismspeaks.org/.../ten-tips-support-me Traducir esta página
Ten Tips to Support Me. Google +. Be a champion for inclusion for all who have autism!
A renowned autism researcher-doctor-advocate asks the autism ...
Population 712,801
Families: 800
Staff: 236 (68% FT)
GIPUZKOA COUNTY POPULATION DENSITY

<table>
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<th>Population density (people per km²)</th>
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GAUTENA: 2016 EUROPEAN CITIZEN AWARD
GRANTED BY THE EUROPEAN PARLIAMENT
1. Embed your program in the community and ensure interdepartmental support

2. Follow best practice guidelines

3. Search for outcome & research

4. Empower service users and family carers

(Caution: not ranked in importance!!)
Message to take home?

THINK BIG, ACT SMALL

GRACIAS / THANKS!!

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