

MY PERSONAL GUIDE

BETA

A tool to help people
get to know me



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get to know me

Pedagogical guide for use by persons with autism and/or
intellectual disability



■ Index

INDEX.....	3
WHO THE PERSONAL GUIDE TOOL IS FOR	5
WHAT IS PERSONAL GUIDE?	6
AUTISM SPECTRUM DISORDERS:	7
INTELLECTUAL DISABILITY	8
DIFFICULTY IN COMMUNICATING PERSONAL INFORMATION.	8
THE PERSONAL GUIDE TOOL.....	10
<i>WHAT CAN BE CUSTOMISED?</i>	<i>14</i>
PEDAGOGICAL GUIDELINES.....	16
<i>PROCESS OF INTRODUCING PERSONAL GUIDE</i>	<i>17</i>
1 Draw up the Introduction Plan for PERSONAL GUIDE.	17
2 Data collection.....	19
3 Introducing PERSONAL GUIDE	19
A TOOL FOR FACILITATING RELATIONSHIPS AND INTEGRATION	21
AUTONOMY IN USING PERSONAL GUIDE.....	23
TECHNOLOGICAL ISSUES.....	24
<i>COMPUTER OR MOBILE TELEPHONE?</i>	<i>24</i>
<i>DOWNLOAD AND INSTALLATION.....</i>	<i>25</i>
ANNEX: ROLE OF THE COORDINATOR AND PARTICIPANTS FOR DRAWING UP THE PERSONAL GUIDE ACTION PLAN.	28
TEMPLATES:	30
CREDITS	35

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■ Who the PERSONAL GUIDE tool is for

The PERSONAL GUIDE tool has been created for use by people with autism spectrum disorders and/or intellectual disability. However, it may be useful for any person who has difficulty in communicating, sharing and expressing personal information verbally.

In this manual we focus on people with autism and/or intellectual disabilities. However, it should be remembered that PERSONAL GUIDE may be useful for many other people.

In this guide we use the term “user” to refer to the person with special needs for whom the application is intended. Similarly, the term “tutor” refers to the professionals, family members or friends who undertake the role of preparing the applications for use by the person who requires them. There is a Manual called “Guide to the Tutor Application” which will be required to guide you through the setup process for PERSONAL GUIDE or any other Azahar application. This Manual is downloaded with Azahar.

■ What is **PERSONAL GUIDE**?



PERSONAL GUIDE has been designed for people with autism and/intellectual disability to communicate personal information to those around them. It consists of an alternative means of communicating tastes, preferences, occupation and any other relevant information, using images. The tool is intended for use in situations where a person with autism and/or intellectual disability needs those around him/her to know things about his/her life.

PERSONAL GUIDE is an aid for portraying basic personal information. It provides the user with a set of images and items which describe essential aspects about him/herself. Used as part of a social skills development programme, it can be useful for working

on the “initiating communication” skill, especially in order for the person to present him/herself to others when meeting them for the first time.

This short manual aims to serve as a guide for parents, family and professionals who live and work with someone who has difficulty communicating with others verbally.

● **Autism Spectrum Disorders:**

Autism Spectrum Disorders (ASD) is a relatively recent term used to describe people with a series of characteristics in common. These characteristics are known as the “triad of impairments” [1]. These people are affected in their ability to [2]:

1. Understand and use verbal and non-verbal communication.
2. Interpret social behaviour, affecting their ability to relate to others. The PERSONAL GUIDE tool is an aid for overcoming this difficulty, at least in terms of starting to communicate.
3. Think and behave in a flexible manner, for example, to adapt their behaviour to specific situations.

Asperger’s Syndrome, High-Functioning Autism, Classic Autism and Kanner’s Syndrome are considered to be sub-groups of Autism Spectrum Disorders [2]. However, people with autism spectrum disorders all tend to be very different in terms of abilities, and strong and weak points.

People with a wide range of abilities may have an Autism Spectrum Disorder, and this may occur in conjunction with other disorders (for example, sensory disability, intellectual disabilities, Down’s Syndrome, ADHD – Attention Deficit Hyperactivity Disorder – or language difficulties).

● **Intellectual Disability**

“Intellectual disability” refers to developmental difficulties causing cognitive disorders and affecting overall intellectual capacity and adaptive behaviour. Adaptive behaviour is understood to be the set conceptual, social and practical skills which we learn in order to live our daily lives correctly. Limitations in these skills affect both daily life and the ability to adapt to changes and demands around us [3]. This disability appears before the age of 18 [3].

The intellectually disabled can have difficulty in communicating aspects of their personal life to others. For this reason, “Personal Guide” can be of great use for this group of people.

● **Difficulty in communicating personal information.**

People with autism present difficulties when it comes to relating to others and initiating communication with them. However, there is a wide variety of levels and capacities in terms of social interaction [4] and communication. Some autistic people find it immensely difficult to communicate with others. Others have been described as “active but strange”, as they achieve certain levels of social communication and interaction, but in a peculiar fashion [5]. These difficulties in social interaction and communication constitute barriers which prevent autistic people from sharing matters with others about their lives (for example, where I live, my name, who I live with, what I like doing, how I communicate, etc.).

The way in which non-autistic people communicate in social contexts creates enormous barriers for those with autism. Being able to tell people what they like, what they do in life, their name, where they live...is something which anyone without autism and/or intellectual disability

does on a daily basis. These skills are necessary for social relationships. PERSONAL GUIDE is a tool which offers the opportunity to communicate personal information using images. Naturally, these images can be customised.

It is important to remember that many autistic people consider themselves to be “visual thinkers” [6], meaning that communication via images can be more accessible for them, particularly if they have not developed oral language skills, or have developed them but do not use them in a functional way.

■ The importance of making contact with others



“When someone new starts at my school, I sit next to them, I tell them my name, what I like doing, and that’s how we get to know each other” “On my first day at work, I introduced myself to all my colleagues and that same night they invited me to a party”. These are skills which are used continuously in social relationships. They are a means of making contact with others in order to be “socially accepted” and share interests and thoughts with other people.

However, many people with autism and/or intellectual disabilities find it tremendously difficult to initiate this type of communication, making it clear what they like, what they do in life, or even saying their name. The ability to communicate with others is a vital part of life. If people with

autism find it difficult to do this, it is necessary to give them the chance to compensate for these difficulties. Technology can be of enormous advantage in this process.

■ The PERSONAL GUIDE Tool

PERSONAL GUIDE offers the chance to communicate personal matters in an accessible and simple way. The application includes a series of optional visual supports which can be used or not, at the discretion of the person in charge of managing the device. These visual supports are used to facilitate the use of different icons or images. Naturally there are a number of adaptations which can be made to facilitate their use, and of course, each user can customise his/her own information, phrases, etc. It is important that this support mechanism is properly planned and it is decided at what moments in life it is to be used, and with whom. The user can gradually learn to use the tool in a more independent way.

The following is a list of proposed moments and people for using PERSONAL GUIDE. Of course, the application can and should be used in many other cases not listed here, but where communication needs to be established with other people.

Moments and people for using PERSONAL GUIDE:

- To communicate personal matters to familiar people at moments in daily life (for example, at home, at work, at school, etc.).
- To facilitate family relationships.
- To facilitate relationships with work/school colleagues and peers...
- When meeting someone for the first time.
- For a new professional (working with the autistic/intellectually disabled person) to have the opportunity to make initial contact with the user.

For a better understanding of the PERSONAL GUIDE tool, here is an example of the above. Let us imagine with a person with autism and/or intellectual disability arrives and his/her usual day centre and there is a new member of staff. The new professional has limited information about that person and barely knows him/her. The user can show that person, using the PERSONAL GUIDE application, some things which will help him or her to obtain basic information such as:

User: Hello my name is Juan



Communication profile: I communicate using images



Likes: I like drawing, I like playing ball, I like brushing my teeth...

And other aspects about the user which will be of great help to the professional in that initial contact.



As we can see, the tool is fundamentally intended for the person to introduce him/herself to others, but immediately after doing so, he/she will need to have more things on hand to communicate. He/she will need to provide more information on some of the aspects included in the personal guide or, if really wanting to reach an adequate level of exchanging information, he/she will need to be able to ask the other people about their interests, likes, hobbies, etc., as anyone else would do in conversations with someone when meeting for the first time. In this

sense, we consider it essential to use this tool as part of a wider communication framework, in an alternative communication system context. We therefore recommend the use of the other applications included under the Azahar programme, such as the HELLO communicator.

The concept of a PERSONAL GUIDE is actually much wider than that covered by this portable application. When working under the Person Centred Planning philosophy, a Personal Guide can contain all the information which people close to the user may need to know. At least this is how the PCP portal “Miradas de Apoyo”¹ works. This portal was developed by the same authors as this tool. This portal includes a section also called *Personal Guide* which covers, among others, basic aspects such as: dreams, fears, strengths, likes, communication profile, etc. Given that it can be difficult to show all this information accessibly on a mobile telephone, for the time being the information included for PERSONAL GUIDE is more limited, only covering the information which may be required by the to present him/herself in everyday social situations. However, in the near future there will be the opportunity to transfer information held on the “Miradas de Apoyo” *Personal Guide* to a mobile phone.

¹ “Miradas de Apoyo”, run by the ADAPTA Foundation, is a web-based group support mechanism for the families and carers of people with special needs, using Person Centred Planning to provide customised support tools via this portal.

- **What can be customised?**

The person responsible for managing the application must adapt the PERSONAL GUIDE application according to the needs of the user. In order to adapt the application as much as possible, the following aspects and parameters can be adjusted:

	Description and options
Learning options	<p>The PERSONAL GUIDE application offers three learning options. These are three levels of complexity which are configured by the tutor depending on the characteristics of the user. It is important to consider that these options can be offered in combination with one another. For example, it is possible to include a shortcut to a photograph on the main screen (one step), plus an icon for a category under which different information can be chosen. This allows a progressive learning process to be created.</p> <p>Shortcut option (one step): An icon appears on the main screen (we advise using a photograph of the user). When the user presses the icon, pre-set phrases are played (for example, "My name is Juan, I go to school and I like eating biscuits" or "Hello, I'm 35 years old, I attend a day centre...I like trains, maps..."). In order to configure this level of learning, the tutor must pre-enter the messages to be used and activate the shortcut option.</p> <p>Category option (two steps): This means an icon is included on the main screen (user photo). Pressing this photo reveals different images representing categories</p>

(for example, likes, dislikes, home, medication...). By pressing on one of these categories, for example "likes", the predefined information will appear for that category (for example: I like cake and I like going to the park).

Advanced option (three steps): This means the image or photo is included on the main screen. Pressing on this icon accesses the different categories (for example, "likes" and "dislikes"). Once one of these categories is pressed, related messages

are shown (for example, "I like cake", "I like playing ball", etc.). The user then chooses the message he/she wishes to transmit.

NB: Up to 4 images can be used to form a phrase, for example: I like doing jigsaws on the computer. See image:



Launch icon
and sound

The image which the user presses to launch the PERSONAL GUIDE application can be customised, resized, and a sound assigned to be played when it is pressed. For example: The user's photo can be used, and set up to play his/her name when pressed, or alternatively a message such as "this is my presentation" or "get to know me".

Personal
information
and
Categories or
Sections

All messages and images which will be used with the application must be customised (for example, pictograms for "I like eating pasta").

At more complex levels, such as category shortcuts or more complicated menu choices, it is possible to customise the number of icons or images which are shown on the screen (for example the categories "likes", "dislikes" "my name" "my toys") and each one can have an associated image which the user understands. However, the application includes a number of images for representing certain categories.

Guide Steps

Inspired by the strategies commonly used in the TEACCH programme [7], there is the possibility of including the steps which will be carried out from the main screen until the customised message is played. These steps contain visual images to be followed and are more numerous depending on the complexity of the application. Examples of advanced structured steps:



■ Pedagogical Guidelines

It is advisable to draw up an action plan for introducing PERSONAL GUIDE. This plan can be used solely for this application or it can be used for the introduction of other similar AZAHAR applications (for example TIC-TAC, or MUSIC, etc.). The people who know the user best should decide what applications are to be introduced, how, when, why and what effect these will have on the life of the person who uses them.

PERSONAL GUIDE requires a learning process for the person who uses it. In order to do this it is also necessary to assess the progress made while using the tool in order to ensure it is being used correctly, that it provides a learning process and that the desired results are being obtained.

● **Process of introducing PERSONAL GUIDE**

As a guideline, we suggest the following process for introducing PERSONAL GUIDE. It is advisable for this Plan to be agreed between all those who are close to the person who is to use the device (family, teachers, and other key people). This group of people need to meet together in order to draw up the plan. Naturally, this Plan should be based on the needs and interest of the person in question, and the user should also make decisions and take part, as far as possible, in drawing up the plan. This work method is known as Person Centred Planning [6] [7]. If desired this process can be carried out via the website www.miradasdeapoyo.org .

A coordinator should be appointed from within the group of people who meet together (preferably an educational professional). The coordinator and all other participants in the group have a role to play as specified in Annex 1 at the end of this guide.

1 Draw up the Introduction Plan for PERSONAL GUIDE.

This guide includes a template (see Template 1 below) for completing this step.

The Plan, which is drawn up in the meetings by the people who are closest to the user, consists of agreeing the following:

- the desired objectives of using the PERSONAL GUIDE application. For example: Improving social skills, offering the use the opportunity to transmit his/her likes to a friend, improving family relationships, etc.

- it is advisable to draw up a list of the situations in which PERSONAL GUIDE will be used, and with whom. this list is completed by the people who know the user best, when completing the action plan. Examples of planned moments and situations may be: using Personal Guide on a Saturday afternoon with a family member, at the day centre with a friend during break time, etc. However, as the user becomes more autonomous and gains initiative in using the application, ideally the moments and people for using it will arise spontaneously.
- images to be used, customised messages, etc.
- The date PERSONAL GUIDE is to be introduced, specifying when new personal information is to be included, or the application is to be used with new people, etc.
- the support mechanism to be provided. For example: Visual supports used in parallel (holding images of the message, strategies for facilitating communication such as encouraging eye contact, etc.).

The information collated will include other aspects such as the user name, the date of the meeting, the name of the coordinator and those attending, and the level of complexity of the application (basic, medium and high) - bearing in mind that the level of difficulty can be increased gradually. All these aspects are covered on Template 1.

Once the Tutor application is running, the level of complexity, colours, sizes and number of shortcuts and other matters should be customised. Furthermore, this adaptation process should include entering the desired messages for communicating personal information. Then save the application, and install only this version on the different devices to be used by the person. Below are a number of guidelines for adapting PERSONAL GUIDE:

If PERSONAL GUIDE is to be used as a shortcut on the main screen (basic level), ideally a photo of the user should be inserted. The user will press this icon in order to view and share personal information messages, previously entered by the tutor, with other people. For example: My name is Juan, I live in..., I like...

If you wish to insert a photo of the user and then a number of different categories under this icon, you should customise the images, sounds and other elements used to represent these categories. At first, it is preferable to use just one category. Later, once the user is accustomed to the process, you can increase the number of available categories. However, the tutor responsible for managing the application will know how best to adapt PERSONAL GUIDE to the needs and interests of the user.

There is a possibility of increasing the level of complexity of this application. This option consists of including a photo of the user on the main screen, and under this, the different categories. The user then chooses a category, accessing the different messages available under that category (for example: under the "like" category, you would find: "I like trains", "I like eating cake"...). Finally, the user chooses the message to be used, although there is also the possibility (if configured by the tutor) of the messages being shown automatically.

It is important to remember that these options (shortcuts, categories, etc.), can be used in combination. For example, the main screen can show one or more shortcuts to personal messages, and at the same time a shortcut to a category under which different messages are shown. This allows us to create a progressive learning process adapted to the needs of each user.

Following the established plan, PERSONAL GUIDE will be introduced for use as a means of facilitating communication at times and with people as identified on the plan, although gradually the user may (depending on each case) learn to take the initiative of using the application spontaneously with other people and at different times.

● **A tool for facilitating relationships and integration**

Communicating personal matters to other people improves the quality of social relationships and facilitates the integration of the person. These are components and indicators of improved quality of life for that person [10].

PERSONAL GUIDE can be useful for facilitating relationships with other people, either known to the user or otherwise. The tool can also be effective in facilitating relationships with peers, acting as a tool for aiding integration. We must remember that many people with autism find it very difficult to relate to their peers. Any social interaction achieved is usually with adults (in the case of young autistic people) rather than with peers (children of the same age). Adults, meanwhile, tend to establish social interaction with the people closest to them, but not with other people of the same age, and when they do, usually find it difficult to interact with them. This tool can therefore be used to encourage this type of social interaction which is difficult between

people with autism and people without. It can also be useful in the relationship between autistic people.

The mere fact of using PERSONAL GUIDE does not in itself mean a communicative action or full social interaction. It is simply a means of *supporting* communication and interaction. For this reason it may be of interest to work with the user on aspects such as: encouraging eye contact with the person they are speaking to, waiting for a response from the other person, facilitating physical proximity and placing them at a similar height, etc. This type of support can be given by the person who is receiving the personal information. This is why it is important that at the outset the user uses PERSONAL GUIDE only at the times, and with the people, set out in the action plan. In this way, we aim for the person with autism and/or intellectual disability gradually to acquire communication skills and autonomy in using the application.

● **Autonomy in using PERSONAL GUIDE**

The person using PERSONAL GUIDE may become more independent in handling the application as he/she learns how to operate it, as the Plan is implemented by all those close to the person and as aspects to facilitate autonomy are included.

While it is desirable for the user to manage PERSONAL GUIDE alone, in the early stages, for certain cases it may be appropriate for the support partner to be the one to use the application. In order to do this, depending on each different person, it may be helpful for the user to see how the tutor uses the device or shapes the entire process (the tutor physically moves the user). In this way, the autistic and/or intellectually disabled person can use PERSONAL GUIDE successfully from the outset.

Gradually the user can handle personal information in a more autonomous way. Ideally the user will develop his/her own initiative to use PERSONAL GUIDE with other people – known or unknown – whenever he/she needs to do so.

■ Technological issues

● Computer or mobile telephone?



The size of a mobile telephone screen can be too small for the early stages of use. For this reason, it is advisable for PERSONAL GUIDE to be introduced using a computer screen. Once the user has become familiar with the programme it can be transferred to portable devices such as Tablets (with touch operated

screen measuring around 12 inches), UMPC's (measuring seven or eight inches) or mobile telephones (just four or five inches).

Ideally the device used should be the same, for example a mobile which he/she can carry around, although at first it is advisable for the person to try out the application on a computer as mentioned above.

If several different devices are to be used, the application must be identical on all of them in order to avoid confusion. At later stages, as the complexity level of the application is increased, remember to update it on all devices in use.

Within the educational process provided for the user (child or adult) small situations can be planned for using PERSONAL GUIDE (for example with a professional at their day centre, or at the

weekend with family). These situations will be when the user accesses the PERSONAL GUIDE tool for the first time. On these first occasions, it is advisable for the application to have just one message for communicating. The number of messages or categories can then gradually be increased. Additional support material, such as the same message on paper, may be of help during this process.

- **Download and Installation**

We have done our utmost to simplify the installation and preparation process for this tool. However, we are aware that for some professionals or family members who have less experience with modern technology, this process may seem complicated. In these cases it is highly recommended to obtain support from a friend or relative who is more familiar with the use of computers and other technological devices.

Detailed steps for installation can be found at: <http://www.proyectoazahar.org>

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ANNEX: ROLE OF THE COORDINATOR AND PARTICIPANTS FOR DRAWING UP THE PERSONAL GUIDE ACTION PLAN.

The group of people should meet together in order to agree on a plan of action for PERSONAL GUIDE. It is advisable to appoint a person from the group to act as coordinator or facilitator. This person will be responsible for directing the plan and ensuring that there is a respectful atmosphere in the meeting, among other roles. The coordinator has the following responsibilities regarding the plan to be drawn up for the PERSONAL GUIDE application:

- in the meeting, all participants, or at least the coordinator, must be familiar with the PERSONAL GUIDE application and its possibilities, explaining to the participants what the application consists of.
- downloading and adapting the PERSONAL GUIDE application at the beginning, and over time (this task can be shared with other members of the group).
- coordinating the record sheets to be used (completing them based on what the group decides, saving them, and drawing results and conclusions).
- calling further meetings to discuss the impact of the PERSONAL GUIDE application in order to make progress with its operation (any other member of the group may call a meeting if necessary).

Despite there being a person appointed to coordinate the Plan, the introduction of PERSONAL GUIDE and other applications is a shared responsibility. The full commitment of all those close to the user when using the device is important for that person to be able to extend the

learning process to all areas of his/her life. We want PERSONAL GUIDE to be used efficiently in the different situations arising in the user's life. For this reason the following tasks should be completed for PERSONAL GUIDE by the group members:

- Providing the support mechanism agreed for PERSONAL GUIDE
- Working together to complete the necessary record sheets.
- Attending meetings required to complete the Action Plan.
- Other tasks required depending on different cases and contexts.

■ Templates:

Each template below consists of key questions and the responses which will serve as a guide for putting the Plan into practice. However, they should be customised for each different situation.

Template 1: Planning

<p>Purpose: To complete an adequate planning process for introducing PERSONAL GUIDE. This planning process is used to specify the objectives, the personal information which will be entered into the application, the images to be used, the date of introduction, moments for use and support partner for the user, in addition to the support mechanisms which will be implemented.</p>
<p>When to use it As a preliminary or planning stage for introducing PERSONAL GUIDE. The planning process should be updated on the mid/long term, as considered necessary.</p>
<p>Who should complete it The members of the group should draw up the plan. These people are normally family, professionals, friends and any other person who wishes to take part in the plan and who have a close relationship with the user of the device.</p>
<p>What are the results used for? The programme coordinator or the person in charge saves the plan and gives a copy to all members of the group at meetings. It is advisable to save this information in digital format, so that all members can access it as required.</p>

User Name:		Date of meeting:	__ / __ / __
Coordinator:		PERSONAL GUIDE application level	Basic/medium/high
People attending

Objectives	Personal information to be entered*	Images to be used	Date of introduction	Where and with whom	Simultaneous support

*For example: Where I live, who I am, my likes, people in my life, my medication, my favourite films, my favourite toys/objects, my activities

Template 2. "Baseline" record sheet for before and during the introduction of PERSONAL GUIDE:

Purpose: To measure, as objectively as possible, the impact of PERSONAL GUIDE on the life of the user.
When should it be used? Before, during/after the introduction of PERSONAL GUIDE.
Who should complete it Those people who are present in the place and situation where PERSONAL GUIDE is to be introduced. Example: teacher, mother.
What are the results used for? Observations are included in the last column specified for this on each record sheet used. At a later stage, when the assessment is repeated after the introduction of PERSONAL GUIDE, the results are compared with the assessment made prior to using the application.
Further observations: Regarding place: the record should be made for the different places where PERSONAL GUIDE is to be introduced.

User Name:		Date:	_ / _ / _
Person who completes the information:		Page number:	
Moment assessment is made:	<input type="checkbox"/> Before using PERSONAL GUIDE <input type="checkbox"/> During or after using PERSONAL GUIDE		
Personal information transmitted:			
Where and with whom:			
NB: As the user becomes more autonomous in the use of PERSONAL GUIDE, he/she will probably begin to use it spontaneously in social relationships, making it difficult to continue recording information on this sheet as these are uncontrolled situations.			

Key Questions	Observations / Conclusions										
<p>QUANTITY OF SOCIAL CONTACT</p> <p>With known people</p> <table border="1" data-bbox="121 687 518 756"> <tr> <td>Not at all</td> <td>A few</td> <td>Some</td> <td>Quite a lot</td> <td>A lot</td> </tr> </table> <p>With unknown people</p> <table border="1" data-bbox="121 839 518 908"> <tr> <td>None</td> <td>A few</td> <td>Some</td> <td>Quite a lot</td> <td>A lot</td> </tr> </table>	Not at all	A few	Some	Quite a lot	A lot	None	A few	Some	Quite a lot	A lot	
Not at all	A few	Some	Quite a lot	A lot							
None	A few	Some	Quite a lot	A lot							

QUALITY OF SOCIAL INTERACTION

Interaction time

None	A few	Some	Quite a lot	A lot
------	-------	------	-------------	-------

Amount of information communicated

None	A few	Some	Quite a lot	A lot
------	-------	------	-------------	-------

Initiative and motivation to communicate

None	A few	Some	Quite a lot	A lot
------	-------	------	-------------	-------

Emotional state of the user

Negative	Neutral	Positive
----------	---------	----------

Reaction of the person with whom he/she is communicating

No interaction	Some interaction	Quite a lot of interaction	A lot of interaction
----------------	------------------	----------------------------	----------------------

Credits



Autism and Learning Difficulties Groups.

Robotics Institute. University of Valencia.

Software development	Arturo Campos Ignacio Navarro Javier Sevilla Alejandro Morell
Coordinator	Javier Sevilla
Pedagogical Design	Gerardo Herrera Raquel Abellán Fabián Amati
Graphic Design of Tool and Guide	Carlos Pardo
Guide Text	Raquel Abellán
Monitoring	Orange Foundation Team

www.proyectoazahar.org

Design and Development



Grupo de Autismo y Dificultades de Aprendizaje.
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