

Williams syndrome and Education, Health and Care Plans: a guide for parents

By

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About this booklet

This booklet aims to:

- Explain the new SEND code of practice (2014) and the Education Health and Care plan process
- Provide a description of the education, health, and care needs of children and young people with Williams syndrome
- Provide some tips and examples of good practice for EHC plans for children and young people with Williams syndrome.

Terminology: words with * are explained in the glossary at the end.

1. The Education Health and Care process

1.1 What is an Education, Health and Care Plan?

In 2014, the new special educational needs and disabilities (SEND) Code of Practice was introduced. One of the key changes introduced by the new SEND framework concerned the replacement of the previous statements of special educational needs by Education, Health and Care Plans (EHCP). An EHCP is a legal document for children and young people with more complex special educational needs (SEN) aged 0 – 25 years old. An EHCP details the child or young person's particular education, health, and social care needs.

1.2 What is the EHCP process?

In order to obtain an EHCP, your local authority must carry out an Education, Health and Care 'needs assessment' for your child or young person. The EHCP process must take no more than 20 weeks from initial EHC assessment to delivery of final plan (see Figure 1 below). You should be able to get from your Local Authority additional information explaining how the process works in your county.

1.3 Who can start the EHCP process?

The following people have the right to start the EHCP process at any time by asking their local authority to conduct an EHC needs assessment for a child or young person aged 0-25 years old:

- the child's parent
- a young person age 16 - 25 years old

- a person acting on behalf of a school or post-16 institution, e.g. a Special Educational Needs Co-ordinator (SENCo) (with the agreement of the parent or young person)
- Any other practitioner working with the child or young person, including a GP or paediatrician (with the knowledge and agreement of the parent or young person)

This means you do not have to wait until your child is in a formal school placement before requesting an EHCP assessment.

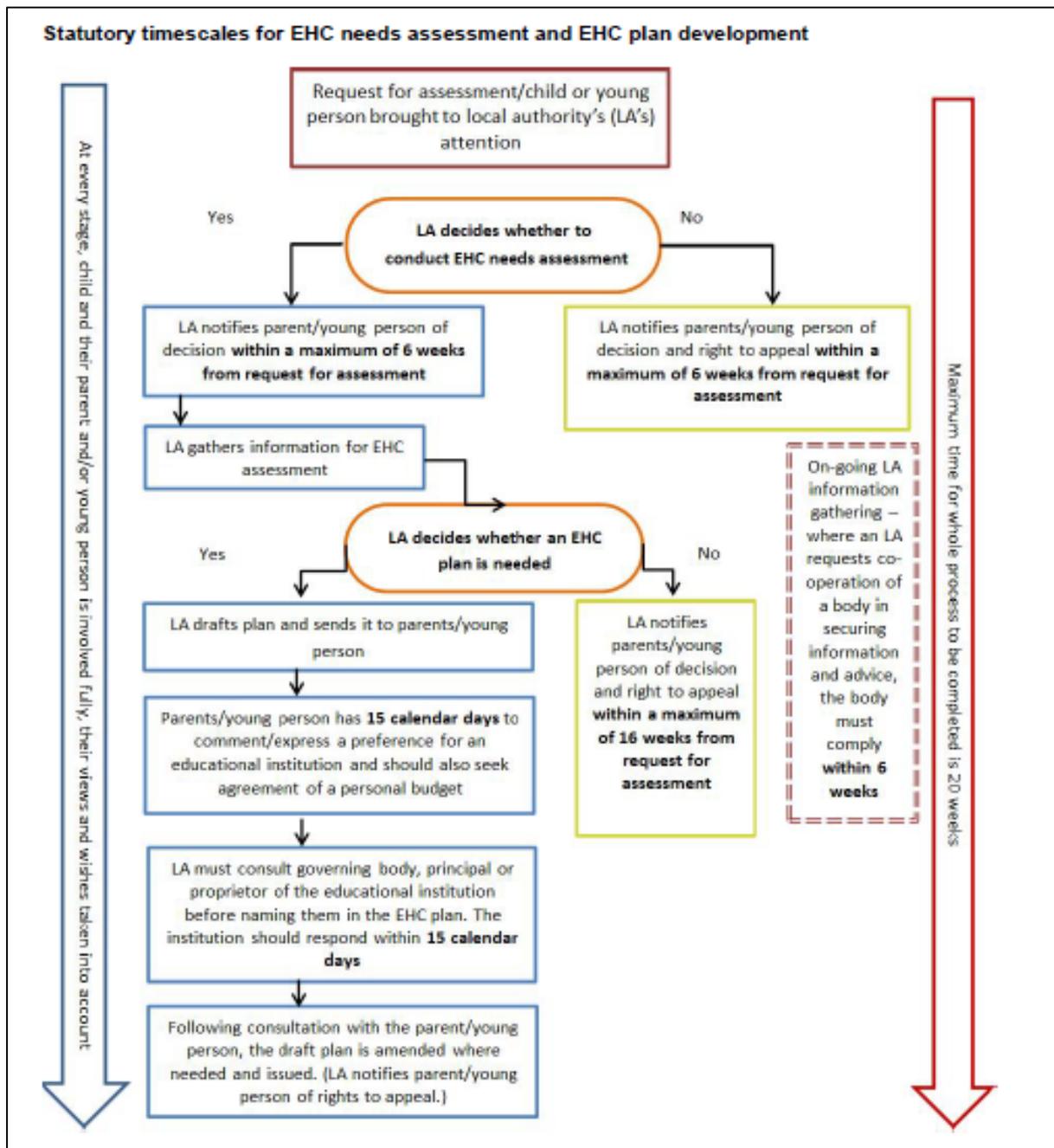


Figure 1. Statutory timescale for EHC needs assessment and plan (taken from Department of Education 2014, p 154).

1.4 What sections are included in an EHCP?

The following sections should be included in an EHCP (see also SEND Code of Practice, 2014, *pg. 161-162*):

SECTION	What's included
Section A	The <u>views, interests and aspirations</u> of the child, or young person, and his or her parents.
Section B	The child or young person's <u>special education needs</u> (SEN).
Section C	The child or young person's <u>health needs</u> which are related to their SEN.
Section D	The child or young person's <u>social care needs</u> which are related to their SEN or to a disability.
Section E	The <u>outcomes</u> sought for the child or young person, including outcomes for adult life. This section also identifies arrangements for the educational setting (early years provider, school, college or other education or training provider), and the short-term targets in the setting
Section F	The <u>special education provision</u> required by the child or young person
Section G	Any <u>health provision</u> reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN. Where an Individual Health Care Plan is made for them, that plan should be included.
Section H1	Any <u>social care provision</u> which must be made available for a child or young person under 18 years of age.
Section H2	Any <u>other social care provision</u> required by the learning difficulties or disabilities which result in the child or young person having SEN. This will include any adult social care provision being provided to meet a young person's eligible needs (through a statutory care and support plan).
Section I	The <u>name and type of the educational setting</u> , i.e. maintained nursery school, post-16 institution or other institution, to be attended by the child or young person and the type of that institution.
Section J	Where there is a <u>Personal Budget</u> , the details of how the Personal Budget will support particular outcomes, the provision it will be used for including any flexibility in its usage and the arrangements for any direct payments for education, health and social care. The special educational needs and outcomes that are to be met by any direct payment must be specified.
Section K	The <u>advice and information</u> gathered during the EHC needs assessment must be attached (in appendices). There should be a list of this advice and information.
<p>If the young person is in year 9 or above... the EHCP must include (in sections F, G, H1 or H2 as appropriate) the provision required by the child or young person to assist in <u>preparation for adulthood and independent living</u>, for example, support for finding employment, housing or for participation in society.</p>	

1.5 What is a ‘Local Offer’?

A ‘local offer’ is published by the local authority on their website. The local offer provides up-to-date information about what education, health, and social care provision is available in the local authority’s area for children and young people who have SEN or who are disabled. The local offer should detail the support available to all children and young people with SEN, such as information about special education, requesting EHC assessments, post-16 education, apprenticeships, school travel arrangements, leisure activities, and personal budgets. The local offer is also available to those children and young people who do not have an EHCP.

Before you have a meeting to discuss your child’s EHCP, please consult your local offer on your LA’s website and discuss with the educational psychologist any provision you would like your child to have access to.

1.6 What is a ‘personal budget’?

A personal budget is an agreed amount of money allocated to an individual by their local authority to deliver provision set out in an EHCP. Young people and parents of children with an EHCP can request a personal budget which has elements of funding for education, health and social care.

For more information about the EHCP process see the leaflet by IPSEA (details at the end of this booklet).

2. The education, health, and care needs of children and young people with Williams syndrome

This section described the general education, health, and care needs of children and young people with WS. This list is not exclusive as no two people with WS are identical, different people with WS may show additional education, health, and care needs. However, you may want to consider some of these needs for sections B, C, and D of the EHCP. Keep in mind that some issues may affect your child’s learning (section B), your child’s health and wellbeing (section C), as well as your child’s social care needs (section D) and should be covered in all three sections.

Finally, when thinking about your child's needs, try and think of a normal school day and the minute-by-minute support they may need (e.g., can they find their way to the classroom, can they unzip their coat and hang up in the right place, would they wander off...). This is not easy, as you may not know what your child does all day in school. So, you may also want to talk to your child teacher(s).

- **Language and communication difficulties:** although language is a strength in most older children and young people with WS, all WS individuals are delayed in their language abilities compared to typically developing peers, and language development is often very delayed at a young age. Under the age of five children with WS show gross motor difficulties and oromotor praxis difficulties, which have both been linked to delayed language and communication abilities. Most young children with WS do not point, which delays language development and communication. In addition, the language abilities in children with WS can be deceptive in that they often produce utterances they have heard before without really understanding these (i.e., echolalia). Therefore, their language comprehension is poorer than their language production and their grammar comprehension is much poorer compared to vocabulary comprehension. These language and communication delays will often result in behavioural and learning difficulties and mainly affect reading comprehension and social abilities.
- **Cognition and Learning:** attention, reading, writing, and number development. Most children and young people with WS have attention difficulties, in that they get distracted easily; find it hard to stay on task; and often focus on social aspects (such as other people's faces) rather than paying attention to the task at hand. This can impact on learning and task completion. Therefore, 1-to-1 support is required to repeat instructions and keep the person with WS on task. Finally, those with WS also find it more difficult to move their attention from one place to another and thus educators should pay attention to where children and young people with WS are looking when giving instructions or teaching new material. Although most children with WS have good phonological awareness*, most have low working memory* abilities and find it difficult to manipulate information in their minds. This can impact on reading using a phonics approach alone. In addition, those with WS have visuo-spatial* difficulties which can impact on their learning of visual stimuli, such as letters and digits. Therefore, reading may be delayed in children with WS and, although some children with WS become fluent readers with lots of practice, they often find it difficult to understand what they have read. Limited working memory abilities also limit children and adults with WS to manipulate numerical information in their minds. Although some children with WS are able to learn numerical facts, such as time tables by heart, understanding of numerical facts and how numbers relate to each other are poor due to a lack of cardinality* understanding and magnitude representations of numbers. Due to the limited working memory abilities and understanding of numbers, memory aids such as abacus and tokens and rote learning of facts are encouraged.

- **Motor delays:** Most children and young people with WS are delayed in their gross motor developmental milestones due to weak muscle tone and show issues with balance. These delays impact on their writing ability but also their physical abilities, such as standing for long time, walking for long distances between buildings or school trips, and navigating busy corridors. Also motor delays may impact on toilet training, getting dressed, and opening packages at lunch and snack times.
- Most children with WS are very musical and respond well to **musical training/therapy** to improve attention, communication, memory abilities, and overall wellbeing.
- Most young children have better auditory than visual abilities and thus benefit from **auditory learning strategies**, rather than visual learning strategies. However, grammatical comprehension is low so instructions need to be kept simple and audio-visual information integration* is poor in WS.
- **Eating difficulties:** Most young children with WS have difficulties eating a wide variety of foods, mainly due to swallowing (caused by motor delay and low muscle tone) and texture difficulties (caused by sensory issues). Due to their motor delays and low muscle tone they also have issues with opening packages, cutting up meat, as well as choking hazards due to low muscle tone.
- Difficulties with **toilet routines and personal hygiene**
- **Overall safe guarding:** people with WS often have limited stranger-danger awareness and can be vulnerable to being taken advantage off. In addition, they may wander off and have difficulties with finding their way around, even in a familiar environment.
- **Sensory needs:** Many children and young people with WS have complex sensory needs including: persistence on routine, hypersensitivity to sounds, restricted interests, sensitivity to certain textures, obsessions and favourite topics.
- **Friendships:** although most children and young people with WS are extremely social and like interactions with others, their relationships with peers are often restricted. Their limited language abilities and limited pragmatic understanding, including what is appropriate within certain contexts and how to maintain a reciprocal communication, may prevent young children and adults with WS from retelling personal stories and building up personal relationships with peers.
- **Inappropriate behaviour:** Your child may talk out of turn, start talking to strangers, wander off, follow their own internal agenda etc. This may affect your child's safety during the school day and school trips as well as social relationships within the classroom. Finally, this also may affect your child's learning.
- **Independence:** Most children and young people with WS have difficulties with working co-operatively, self-organisation, and planning or time management and thus, most young adults are not able to plan their day and routines and struggle with living independently, including understanding the value of money.
- **Slow growth rate and small stature**
- **Anxiety and mental health issues**
- **Congenital heart defects**
- **Anxiety and renal issues** might mean that your child needs toilet breaks more frequently
- **Dental anomalies**

- **Visual problems:** your child may benefit from sitting at the front of the classroom and may need adapted worksheets.
- **Auditory problems and hypersensitivity to noise:** your child may find certain noises difficult to cope with and may need access to a quiet room for learning or ear defenders to help with noise regulation.

Professional advice and specialist help

Due to these difficulties, children and young people with WS age 0 – 25 years old may often need additional educational provision and specialist help from external services, including:

- Speech and Language Therapy (SLT) assessment and intervention
- Educational psychologist assessment
- Occupational therapy (OT) assessment and intervention
- Assessment and intervention to address sensory impairments (e.g. Sensory impairment team)
- Physiotherapy assessment and intervention
- Specialist help to cope with anxiety
- Specialist advice on ICT.
- An adjusted learning programme provided by an Educational Psychologist
- Dietician
- Auditory consultant
- Social worker
- Health professionals: including cardiologist, ...
- Additional staffing within the school, to enable focuses learning and participation under the direction from the teacher
- School staff to be trained in the specific learning profile and approaches to learning that effectively support children and young people with WS

3. EHC plans for children and young people with Williams syndrome:

Sections A, E, F and I

This section considers some more detailed information about the different sections of the EHCP, especially section A (the voice of the child), section E (outcomes), section F (provision) and section I (the educational placement).

3.1 Section A: the voice of the child

An EHCP should represent your child's views as well as those of the parent. This includes what they are good at, what they have difficulties with, how best to support them as well as their future aspirations. Although almost all children with WS are delayed in their language

development and understanding, below are some ways in which a child's voice and future aspirations can be captured in a meaningful way. In addition, EHCPs should describe what method was used to describe the child's voice and advise on the best ways to communicate with the child.

Tools to elicit and capture the child's voice:

In addition, to just asking the child about what their good at, their limitations and aspirations. Below are some further tools that can be used to elicit the child's voice.

- **Scaling:** Visual number scales from 0 to 5 with sad to happy faces can be used for children to rate their opinion on different aspects of life at school or home. The ratings can be noted or used to direct further discussion.
- **Audio:** An audio recording of a discussion with the child about their likes dislikes and aspirations can alleviate the pressure of the child writing their views, and provides an accurate representation of the discussion had with the child for EHCP meetings and annual reviews.
- **Video:** Similar to the audio recording, a video recording of the child could be taken and presented as another accurate representation of the child's views at EHCP meetings and annual reviews. In addition, children could be asked to make a video of their likes, dislikes and their aspirations.
- **Photos of child:** Taking photos of the child's achievements, engaging in activities and with friends and family is another good representation of the child's voice. Such photos can also be put into Section A to showcase what they are good at and what they like.
- **Picture/symbol communication:** Children can make a choice from a range of symbols/images to show their view or preference on different topics. The choices can be noted down, or someone can put a tick or cross next to each picture shown to the child to indicate what they like or don't like. These images could be taken from other tools that are already familiar to the child such as a visual timetable.
- **ICT (e.g. PowerPoint presentation):** Some children or young people might enjoy making a short presentation with assistance about their interests, achievements, and hopes for the future using pictures and/or videos as examples.
- **One page profile:** This can be used to summarise the important information about the child on one page and engage the child's views using a few simple headings such as 'What is important to me' and 'How best to support me'. This can be useful for people working with the child to quickly understand what matters to the child.
- **Use camera/GoPro devices:** Technology like this can be used to gain special insight into a child's world by attaching it to the child (e.g. on a body harness or hanging around their neck) and setting the device to record or take photos continuously throughout the day.

Doing this can reveal what the child particularly enjoys doing during the day, and shows the people, pets, and places that are important to the child.

- **Use of toys:** The child's toy/toys could be used as an extended voice of child as they pose a non-threatening proxy to communicate different views by. Toys could also be used in role play to represent different people or situations and gain an understanding of the child's view of such topics.

3.2 Section E: outcomes.

This section should clearly describe the long-term outcomes for your child including: how these outcomes will be achieved, when these outcomes will be achieved, and who will assess the outcomes. In sum, outcomes should be SMART: specific, measurable, action-orientated, realistic and time-framed. Finally, outcomes should be forward thinking, especially in relation to transition to adulthood.

For example, it is not good enough to state the following outcomes:

- *To improve the child's gross and fine motor skills*
- *Develop early literacy and numeracy skills, to count and write independently.*

In both of these examples, the outcomes are too broad and it is not clear how the progress can be measured. It is also not clear what tools will be used to develop the child's skills, who will help the child, how often the child will receive help, and what the deadline is to have this outcome achieved.

Examples of SMART outcomes:

- To improve expressive language skills to produce a range of words. X will attend Speech and Language Therapy sessions once a week within a group session and school staff will use symbol communication daily to support language understanding and development too. X will be able to utter 5 word vocalisations by the next annual review in November 2018.
- [what]: gross motor skills will show improvement. [how]: swimming lessons, horse riding, the use of OT programme and specialist equipment in class. [By who:] Class

teacher, keyworker, parents. [By when:] November 2018 [Achieved:] X able to climb stairs using feet, hop on one leg and step over objects.

3.3 Section F: Special Education Provision

This section details the specific special educational provision required by the child at school. This is a very important part of your child's plan as it is legally binding and needs to be detailed enough should your child move schools etc. Therefore, this section should include the type, amount (specified in hours per week) and frequency of support required in relation to the child's needs outlined in Section B.

Consider the following two examples:

- *X will be receiving 25 hours per week of 1-to-1 support during class-based work.*
- *X should be receiving extra help*

The example, 'X will be receiving 25 hours per week of 1-to-1 support during class-based work', suggests that the child will not receive any help during break or school-trip times. In the example, 'X should be receiving extra support', the hours of support are not specified and thus the school is not bound to provide as much as you may like.

3.4 Section I: The Educational Placement

This section should state the name and type of educational placement the child will attend. During the stage of drafting the EHCP, the parent or young person can name the type of school or college they want (mainstream school or special school), and also name a specific school they want to attend if they have one in mind. The local authority then has a legal duty to ensure that the educational provision named in the EHCP is secured and delivered.

How to get the best deal

- 1) Start the EHCP process as soon as possible as delays are not uncommon (especially when your child is transitioning to a new school/ new local authority)
- 2) Do your research: Start by looking at the provision within the school and the local offer on your local authority's website. Take notes about what provision you want for your child.
- 3) Provide your educational psychologist and local authority with information about Williams syndrome (see information available from Williams Syndrome Foundation website)
- 4) Gather evidence from relevant professionals. You should not need to access professionals privately but GPs, paediatricians and other professionals can provide valuable input about your child's development and needs.
- 5) Consult the SEND code of practice guidelines (see the leaflet by IPSEA).

The new SEND code of practice is all about giving parents more input into their child's provision but that also means that the more action parents take and the more information about the process and your child, the better the results you will get for your child.

4. How do you resolve issues around the EHCP process?

There are several steps to consider when trying to resolve any SEND disagreements:

- 1) Try and resolve any issues by having informal discussions and meetings with school staff and/or LA SEND staff. These informal discussions and meetings would normally be expected as the first step in seeking to resolve any issues or disagreements relating to SEND.
- 2) Consult the SEND Information, advice and support service (IASS or SENDIASS4). Every LA must provide or commission an impartial, confidential and accessible information, advice and support service for children, young people and parents in relation to SEND. The scope of the service is set out in the SEND code of practice, 2.17-19 (DfE, 2015). It includes offering informal support to resolve disagreements and help in managing mediation, appeals to the First-tier Tribunal SEND and complaints relating to SEND.
- 3) Consult the complaints procedures in the SEND code of Practice. All public services must have a complaints procedure. Those relating to educational settings in general and to SEND issues in particular across education, health and social care are summarised in the SEND code of practice, 11.67 – 11.111 (DfE & DH, 2015).
- 4) Contact the Disagreement resolution service. Every LA must commission an independent disagreement resolution service (DRS) available to parents and young people. It covers all children and young people with SEN (not only those being assessed for or having an EHC plan). It may be used in relation to four types of disagreements that cannot be appealed to the First-tier Tribunal SEND. These four

specific types of disagreement are set out in the SEND code of practice, 11.8 (DfE, 2015 see also Figure 15).

- 5) Contact mediation service: Every LA must commission an independent mediation service that is available to parents and young people. Before making an appeal to the First-tier Tribunal SEND, unless the application is about placement only, parents or young people must contact the mediation service to discuss whether mediation might be a suitable way of resolving the disagreement (this is known as 'mediation advice'). The subsequent decision whether or not to take-up mediation is voluntary for parents or young people. If mediation is chosen, the local authority must ensure the meeting takes place within 30 days of being informed. Further information is provided in the SEND code of practice, 11.13 – 11.38 (DfE, 2015).
- 6) Taking up the issue via a First-tier Tribunal: SEND Specific decisions relating to EHC needs assessments, specific aspects of the content of EHC plans, or the decision to cease an EHC plan can be appealed by parents or young people through the First-tier Tribunal SEND (SEND code of practice 11.45, DfE, 2015 – for further information about appeals, see sections 11.39 – 11.52).

(Information taken from: Cullen, M.A., Lindsay, G., Totsika, V.,... and Miller, A. (2017). Review of arrangements for disagreement resolution (SEND). London: Department of Education; Ministry of Justice, page 18)

Further Reading and information:

For further information please consult the following guidelines:

- **Medical guidelines published by Williams Syndrome Foundation:**
<http://www.williams-syndrome.org.uk/system/files/articles/2016-05/pub5-clinical-guideline.pdf>
- **Anxiety issues in Williams Syndrome:** http://www.williams-syndrome.org.uk/system/files/articles/2016-07/wsf_riby_anxiety_primary_1.pdf
- **Full SEND code of practice:**
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf
- **SEND Guidelines for parents:**
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417435/Special_educational_needs_and_disabilities_guide_for_parents_and_care_rs.pdf
- **IPSEA Independent advice for EHCPs:** <https://www.ipsea.org.uk/what-you-need-to-know/ehc-needs-assessments>

For further information about the outcomes of the RASE, Raising awareness for Special Education for WS (Van Herwegen & Palikara, 2017), please see www.jovanherwegen.co.uk

Glossary

- **Audio-visual information integration:** the process of integration of visual and auditory information by creating a connection between what one sees and what one hears.
- **Cardinality:** is the understanding of counting, or knowing that the last number counted refers to the number of elements in a set or other grouping, as a property of that grouping.
- **Oromotor praxis:** the ability to plan and co-ordinate movements of the speech articulators (i.e., mouth, tongue, teeth and glottis).
- **Phonological awareness:** is one sub-area of phonological processing that allows detection and manipulation of sounds.
- **Pragmatic understanding:** how language is used in a context and conversations. E.g. knowing when to tell a joke, when to listen to other people, when to ask for more information.
- **Pre-teaching:** is teaching the child the concepts and vocabulary required before a classroom activity, either at home or in the class.
- **Reciprocal communication:** Communication is a two-way, reciprocal process. We communicate with others to make our needs and desires known, and others communicate back to us to acknowledge and respond to our needs.
- **Visuo-spatial abilities:** a range of cognitive processes that allow the capacity to understand, reason and remember the spatial relations among objects or space. Visual-spatial abilities are used for everyday use from navigation, understanding or fixing equipment, understanding or estimating distance and measurement, and performing on a job
- **Working memory:** a cognitive system that is part of memory and allows the short term storage and manipulation of data. For example when adding up two numbers in your mind.

Acknowledgements

The guidelines in this booklet are the result of a research project that examined the implications of the new Special Educational Needs code of practice (2014) for people with Williams syndrome. We would like to thank the Williams syndrome Foundation for funding this research project. We would also like to thank all of the families who have taken part in the research. Special thanks go to Joanna Whale and Laura Lovell for their helpful suggestions.

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