

FEEDBACK ON DIGITAL USE BY PARENTS, PROFESSIONALS AND CHILDREN WITH ASD

COUNTRY REPORT UNITED-KINGDOM / IRELAND







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The UEFA Foundation for Children (**www.uefafoundation.org**) was established on the initiative of the UEFA's desire to play a more active role in society. The Foundation, which is a public body governed by Swiss law, was formally established and began operating the 24th of April 2015. For years, the governing body of European football has been supporting initiatives and programmes that help children in difficult circumstances, working with numerous different partners to develop projects across Europe and beyond. The foundation aims to help children and safeguard their rights. Sport, and football in particular, can provide support in the areas of health and children's education, as well as promoting access to sporting activity, facilitating children's personal development and fostering the integration of minorities.

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The mission of the FIRAH (Foundation of Applied Research on Disability) follows two main directions, which are complementary and merge:

- 1. The call for projects: selection and funding of applied disability research projects.
- 2. The coordination of the Resource Center. Internationally concerned, the Resource Center Applied Research and Disability aims at creating connections and bonds between researchers and field stakeholders¹. It develops and disseminates research in order to promote an inclusive social transformation and to facilitate the full involvement of persons with disabilities.

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¹ Field stakeholders: Persons with disabilities, their families, and their representative organisations. Any Human Rights organisation working with persons with disabilities. Service providers and other organisations working with Persons with disabilities. Service providers and other organisations working in mainstream that are required to the meet the needs of persons with disabilities such as architects, teachers, companies, industries etc. Researchers and research institutes. Local, national and international decision makers.

In partnership with:



Autisme-Europe aisbl (**www.autismeurope.org**) is an international association whose main objective is to advance the rights of people with autism and their families and to help them improve their quality of life. It ensures effective liaison among almost 90 member autism organisations in from 38 European countries, including 27 Member States of the European Union, governments and European and international institutions. Autism-Europe plays a key role in raising public awareness, and in influencing the European decision-makers on all issues relating to the rights of people with autism. Self-advocates and parents play a central role in our organisation to ensure that the views and interests of persons with autism are adequately reflected in our work. We are also regularly consulted by the World Health Organisation (WHO) and cooperate with the United Nations (UN).

Members of the working group

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The Autism and New Technologies Program

An action-research project has been launched by FIRAH, and is being conducted by INSHEA, the University of Mons and University of Paris Sud-Créteil, the National Autistic Society, the Haute école de travail social et de la santé (EESP | HES-SO), and the Fondation Autisme Luxembourg.

This three-year collaborative programme is an opportunity to share knowledge and practices concerning the use of new technologies for children with Autism Spectrum Disorder (ASD), aged from 2 to 18 years.

The project has three major themes:

- Improve access to educational material and equipment developed with new technologies and adapted to specific needs for children with ASD and their families, such as robots or tablets.
- Increase awareness and train famillies and professionals in the best support for children with ASD in their use of new technologies. Guidebooks are available to families and professionals.

• Design and carry out applied research projects on the needs and expectations of children with ASD and their families, and provide concrete answers for their daily needs. This means evaluating the impact of the use of new technologies on children with ASD, to improve available material and applications. The approach is participatory, involving the children, parents and professionals working alongside the researchers.

Online questionnaires were given to children and adolescents with ASD, to their parents, and to professionals working with these children on the use of new technologies. The aim was to gather feedback on the use of new technologies. The questionnaires included questions on the digital tools and method of use, the different areas (educational, communication, logic...) in which they were used, appropriation, and specific questions on verbal communication and social interactions. The questionnaires were filled in by 111 professionals, 137 parents, and 90 children or adolescents with ASD, from Belgium, France, Luxembourg, United Kingdom and Switzerland.

The present report is a synthesis of the responses received from the questionnaires in United-Kingdom and Ireland. Tracey Sellers and Holly Judge (The National Autistic Society), members of the working group, worked on this report.

Organizations, units and schools partners of the Autism and New Technologies Program in UK and Ireland: School of the Holy Spirit, Longstone School, St Mary's National School, Thames Valley School, Hellen Allison School, Fosse Way School, Inver N.S., NASAT Church Lawton School, Thomas Bewick School.

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1. METHODS

A link to each of the 3 versions of the questionnaire (*one for children & adolescents, one for parents and one for professionals*) devised by INS HEA and FIRAH, was emailed to each of the liaisons for the 9 schools in the UK and Ireland in January 2017.

The survey was re-opened in March 2017 and each of the school liaisons (for the project) were followed up with by telephone. This was to attempt to ascertain how many surveys they think were completed for their school, to encourage them to re-circulate the survey and offer any assistance

The quantitative responses (with a yes or no scale) in the surveys were aggregated in excel and calculated as percentages. The verbatim responses were assigned themes according to a coding framework, counted and listed in order of occurrence.

Some anonymised comments were also utilised from feedback emails from school liaisons we received after survey closure. This was mainly in reference to context of use of digital tools that had recently been purchased.

The report below describes the basic demographics (age, type of school, profession, diagnosis) of each of the three types of respondent. A descriptive summary of the communication and social profile of children supported in relation support with and without the aid of digital tools. Followed by a description of favourite tools & applications, liked & disliked featured, context of use, technical difficulties faced and experience of use.

Each of the descriptive summaries are divided into the perspectives from the three cohorts.

2. SUMMARY

- Across the **9 partner schools** (6 in the UK and 3 in Ireland) there were a **total of 25 and 17 surveys completed** (including all three versions of the survey). 30 incomplete surveys in English were identified in the survey platform.
- **Overall demographics:** Age range was from preschool (5 years old) to post-16 college (18 years old), including a mixture of mainstream with SEN/ASD units and specialist schools. Professionals range from resource teachers, from therapists to assistant principals.
- **Communication and social profile**: Varies from those who have limited verbal communication (require visual aids and use gestures) to those who are more self-sufficient in interacting both in both family and school environments
- **Favourite tools:** range from a variety of hardware (ipads, laptops and smartphones) to software applications (Microsoft packages, organisational, learning and games apps).
- Use for digital tools: Use both for learning in the classroom and entertainment/leisure at home (especially the UK). Teachers report that it can sometimes be difficult to motivate appropriate use at school, with obsessive behaviour playing a role.
- Application to Autistic profile: Professionals in particular illustrate how certain platforms can facilitate group interaction, social skills and problem solving. Software applications on ipads can be especially beneficial for promoting independence through daily scheduling and organisation as well as circumventing difficulties with manual dexterity. Use of applications for students who are non-verbal or who have limited language was also prominent, although it's unclear how effective this is.
- **Technical difficulties:** Are often experience such as difficulty with internet/Wi-Fi connection, cost and general malfunction. Reliance on IT and lack of training were also significant limitations.
- **Experience using digital tools** ranged from 5-7 years in the UK schools and 1-3 years in the Irish schools. Use is daily for most pupils and has a direct impact on learning and emotional wellbeing

3. SUMMARY OF SURVEY COMPLETED BY CHILDREN & ADOLESCENTS

3.1. Demographics and profile

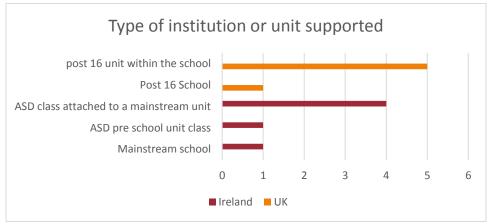
3.1.1. Who responded?

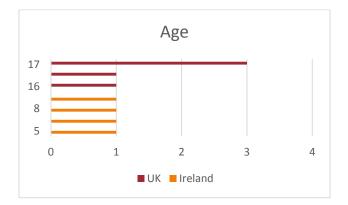
7 children & adolescents from the UK and 6 from Ireland (13 incomplete responses were in English).

3.1.2. DemographicsAge range was from 5 to 18 years.All UK respondents were 16+ years and in a post-16 school unit.

In regards to Ireland however, all respondents were **below 16 years** and attending **pre, primary and secondary mainstream schools** with *associated SEN or ASD units*.

Graphs illustrating type of institution and age of children:





3.2. Non-verbal communication and socialisation

In response to questions on communication and social profile:

14% and 25% of respondents (of UK and Ireland respectively) report that they have *difficulty understanding other's emotions*.

Comments given included :

- 'I am not always aware of how others feel or how I make them feel' (11 years, mainstream school, Ireland).
- 'Reading facial and social cues. Paying attention to conversation. Expressions and tone of voice' (16 years, post-16 school, UK).

0% and 20% (UK and Ireland) admit they have 'difficulty interacting with others', with one 11 year old from a UK mainstream school citing that it is because they 'sometimes have difficulty understanding others'.

This however is contradicted by the **17% and 60%** (UK and Ireland), who responded yes to the question *'Do you have any difficulties knowing what to do with other people in certain situations?'*

- This was illustrated by one comment from the UK: 'What to say and what is socially acceptable/appropriate' (16 years, post-16 school).
- Along with three comments from Ireland : 'They don't understand my points all the time' (11 years, Mainstream School),
- 'Sometimes other children try to play with me and I don't know what they are doing' (8 years, special class).
- 'I can be over enthusiastic' (5 years, pre-school unit).

Its' speculated that contradiction of responses compared the preceding question could be attributed to interpretation and specificity of question phrasing.

Support with communication and socialisation

There was strong agreement (100% UK and 60% Ireland) that there is **support in education and in the** family with developing social skills.

The examples given includes:

- General 'lesson activities', which had 5 mentions from UK participants.
- A 'Social skills programme' (E.g.: social stories), which had 2 mentions from Ireland.
- 'Talking to family' and 'Games/activities assisted by adults' were each mentioned once by UK and Ireland respectively.

In response to 'Do you feel that the use of digital tools helps you to better understand how to behave with others in certain situations?'

83% of British participants said yes but only just 33% of Irish participants agreed with this.

3.3. Digital tools

3.3.1. Favourite digital tools and applications

For the UK and Ireland, the following hardwire devices were cited (in order of popularity) :

- Mobile Phone/Smartphone
- iPad/tablets
- Personal computer
- Laptop
- Xbox/games consoles such as PS4

In terms of applications to download and play on hardware, the following were cited in order of popularity:

υκ	Ireland
Youtube	Youtube
Email (including gmail) and imessaging	Educational skills software/downloads e.g.:
	Starfall and Baggin the Dragon.
Star wars app/game	Online building games (block or mindcraft)
Facebook, Instagram and social media (as a	Video games e.g.: Thomas Go Go and Sonic dash
general medium)	2 – sonic boom
Online entertainment e.g.: BBC App/iplayer and	Online entertainment network e.g.: Netflix and
movie/music apps	Nickplay.
Google search engine	
Memos	

For both UK and Ireland, children listed a verity of reasons why the liked the above digital tools:

- Can contact friends/family
- lightweight, internet
- Listen to music
- Easy to use
- Storage space
- Games are fun.
- Fast/efficient.
- Can build things
- Big screen.

3.3.2. Disliked features included:

- Short battery
- Slow loading
- Freezes/crashes
- Poor internet/wifi connection
- Not enough memory/storage
- Screen can break.

3.3.3. Context and use of digital tools

70% of UK respondents described their **use of digital tools across variety settings** (both work and leisure at school and home, but with the **Irish respondents** (only 33% said yes) use tended to be more **singular** (only just in school or home).

As a result, for the **UK the top three uses** of digital tools were for *communication, creative activities* e.g.: drawing and music etc) and *games & leisure*, which reflects the frequent home use.

For **Ireland the top three uses** were much more education focused i.e.: for *school work* (e.g.: reading, maths etc), to *support fine motor skills & dexterity* and *games & leisure*.

3.3.4. Experience using tools

All respondents described their use as daily and weekly, with on the *UK* having on average 5+ years' experience of using digital tools, with *Ireland* having 3+ years' experience.

4. PARENTS

4.1. Demographics and profile

4.1.1. Who responded?

6 parents from the UK and 3 from Ireland (11 incomplete surveys were in English).

4.1.2. Demographics

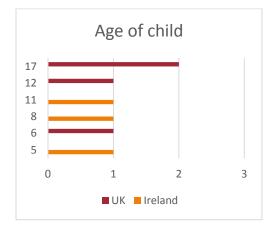
For both UK and Ireland profession of parents included: teacher, Healthcare worker, university professor or just carer/parent.

Age of parents ranged 36-54 years for the UK and 29-45 years for Ireland. Where as their **child's age** ranged from 6-17 in the UK and 5-11 in Ireland.

All children of parents were simply cited as having an 'Autism Diagnosis'.

Graphs illustrating profession of parent and age of children:





4.2. Non-verbal communication and socialization

In regards to the communication profile, **each parent cited different issues** impacting their children in this area.

For the **UK** this included generally 'reading people' and knowing what is appropriate in terms of response. Emotional expression and expressing desires were also factors affecting commination.

With Ireland there was more focus on responding to social cues via eye contact, facial expressions and pitch or tone of voice. Getting needs met and understanding instructions were also references.

In response to the question: 'What is your child able to do with respect to non-verbal communication?', again there were a range of mentions including signing, gestures and use of PECS (Picture exchange communication system).

One comment from the UK highlighted in just one case how the parents interpret communication through mood rather than explicit non-verbal gestures: *'My child has limited non verbal communication. They like routine, and it is basically the same every day. Their best non verbal communication is their mood.'- carer of 17 year child*

When is comes to **initiating social interaction**, *UK respondents* commented that their children have limited social interaction as '*He operates alongside people rather than with them*' (University Professor and parent of 17 year old), '*Limited at school/college and with family*' (career of a 17 year old) or '*Can't, has no Friends*' (Mother of 6 year old).

The Irish cohort had more positive examples such as '*Will join in chasing games with sibling, peers, adults to best of his ability. Turn taking in simple games*' (Teacher and parent of 8 year old), '*He is getting a lot better. He joined other club, Stays over at other peoples' house and mixes a lot better*.' (Health Care worker of an 11 year old) and '*He plays with his school friends*' (Career of a 5 year old)

According to the parents the main difficulties identified that keep their children from interacting optimally mainly alluded to '*just the communication and social skills profile'* associated with autism as a whole. More specific examples for both countries were in relation to judging and responding appropriately to situations, turn taking, use of language and general confidence/ease in company.

4.3. Application of digital tools to social and communication skills

25% and 33% (UK and Ireland respectively) said that the use of digital tools is part *comprehensive plan to develop* non-verbal communication skills. Examples given for Ireland were more focused around encouraging and developing speech, such as use of a PECS online application.

For both countries use of visual timers and learning applications i.e.: Proloquo grid player (for organisation and developing vocabulary respectively).

In terms of including **development of social skills in an Individualised Education Plan**, there was much **stronger agreement from Ireland** (67% said yes).

Regarding the type of plan, one commenter found this very helpful: '*It does help especially when the child is so into technology*' (Carer of 5 year old) and another gave an example: '*Going Places - videos for modelling social skills*' (Teacher and parent of 8 year old).

There was high agreement that support *fostering social skills with digital tools* is applied both across the **school and family home environments**, and progress is relatively the same in these settings (only Ireland responded to this question).

There was only one example given from Ireland of an actual tool used to develop social interaction: '*Phone was the best, none of the other children had one and they all wanted it*' (Healthcare worker and parent of 11 year old).

In response to how certain digital tools can hinder social interaction, there was especially strong agreement in the UK in relation to obsessive behaviour that can develop, as one commenter simply highlighted: 'Any addictive technology does this' (university Professor and parent of 17 year old).

4.4. Digital tools

4.4.1. Children's and parents favourite applications.

For the UK and Ireland, the following hardware devices were cited (in order of popularity):

- ipad/tablet
- iphone/smartphone
- Perosnal Computer
- Laptop/Macbook
- Games consoles such as PS4
- Smart TV (internet connected television)

In terms of applications to download and play on hardware, the following were cited:

UK	Ireland
Online games e.g.: Pokemon Go, Mario run	Online games e.g.: Mario, Fifa, puzzle games
Youtube and online programmes	Autism specific educational applications e.g.:
	Buddy Bear Autism ihelp and grace app.

Digital music service e.g.: spotify	Applications for daily scheduling and
	organisation e.g.: choiceworks
Email	Online building games e.g.: mindcraft
iphoto	Educational skills software/downloads e.g.
	phonological awareness

4.4.2. Most liked and disliked features of digital tools:

Respondents from the UK, made *most reference to the features of types of* hardware e.g. : ipad, PC. Most liked features were that it simply provided a means of interaction, was easy to use, accessible and **portable** when applied to tablets and phones.

Whereas the Irish respondents made *most reference to the features of applications/software.* Most liked features included that they were **age appropriate, fun, educational**, **a good reinforcer** and **helpful for organising routines**.

Most *disliked features* of tools for most respondents were that types of hardwire tended to have **short battery lifes**, **high cost and incompatibly with other brands** if there was a need to share an online platform.

Dexterity when using a mouse pad and **obsessive behaviour** or **addiction when using** could also be problematic.

4.4.3. Context and use of digital tools

Respondents from the UK made **reference to a wider context for using tools** from research, to school work & organization to entertainment in school and at home.

Respondents from Ireland only made **reference to educational use** for learning and developing communication & social skills.

In the educational setting the top 4 categories of use for both UK and Ireland were for *academic skills* (writing, reading, maths etc), *organisation & problem solving, creative activities* (art, music) and *games & leisure*.

Switching context for home e.g.: from entertainment purposes to educational use could sometimes for difficult especially for the Irish respondents who have younger children. Comments included: 'Sometimes can be reluctant to use it for learning' (Carer of 5 year old) and 'Often on own agenda and flicks forward / back' (teacher and parent of 8 year old).

Regarding frequency of use, digital tools are **used daily** and experience ranges from **2-7 years for the UK** respondents and **1-2 years for the Irish respondents**.

Applications were sometimes used with other family members, and generally purchased by the family via recommendations from professionals or through browsing app stores.

5. PROFESSIONALS

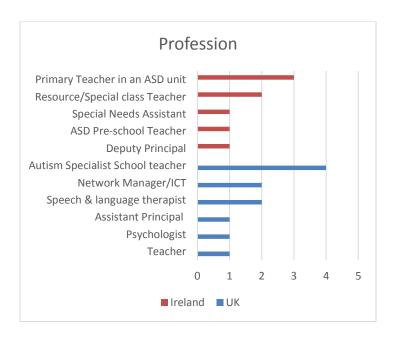
5.1. Demographics and profile

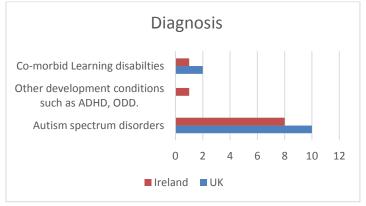
5.1.1. Number of respondents

12 professionals from the UK and 8 from Ireland (6 incomplete surveys were in English).

5.1.2. Demographics

A wide range of professionals from the UK responded to the survey, including: teachers in specialist schools, assistant principals, psychologists, speech & language therapists, IT/network managers. Whereas respondents from Ireland only included school teaching staff and leaders: primary and resource teachers, re-school teachers, deputy principals.





5.2. Non-verbal communication and socialization

In relation to the communication profile of children & adolescents supported the **top four issues described** were in relation to *responding and expression for those with limited language* (even when using PECS), *expression of emotions through facial expression* (as well as interpreting in others), **managing emotions** and *responding appropriately to social cues* (that many to be picked up on to begin with).

Interestingly some professionals expressed that **interpreting behaviour and needs of children** supported was **sometimes difficult from their perspective**.

As often observed with the broadness of the spectrum, students with high functioning autism were generally described as '*More comfortable interacting in class and break times*' and could '*Interact with all individuals competently most of the time*'.

Whereas those with **severe learning disabilities** tended not to interact at all or '*play alongside and not* with each other'.

Regarding difficulties with social interaction the **UK** cited '*lack of motivation to interact/having different desires'*, *level of understanding* and '*awareness of others*' (as separate from self)' as the main issues for the people they support.

Ireland made most reference to *lack of speech*, a *reluctance to share or take turns* and *level of understanding & literal interpretation* is the main issues.

Most importantly **many professionals highlighted** that '*each student is different and needs are diverse*', so therefore any sweeping generalisations should be avoided regarding profiles of abilities across the spectrum for the purposes of this report.

Support for Non-verbal communication and socialization

Overall there was **strong agreement** (82-50% UK-Ireland) **support is provided** to develop communication and social skills *without the aid of digital tool*.

Examples given included group activities to facilitate interaction and increase attention, along with use of social stories and extra teaching time. Use of one to one and targeted therapeutic support (speech and language therapy and occupational therapy) were also mentioned. For pupils who are non-verbal there is some reliance on the use of gestures and signing, as well as pointing and guiding by hand.

Only 50-25% of UK and Irish respondents admitted to a *comprehensive plan being in place when developing communication and social skills using digital tools*. Examples of some of the reasons being 'The children get the opportunity to learn skills that they can then apply with everyone else around them' (ASD Pre-School Teacher, Ireland) and 'The digital tool is one part of a multi faceted programme to *enable the pupils to use different forms of communication to allow them to communicate immediately* without having to rely heavily on one method' (SEN Teacher, UK).

Most **popular uses of digital tools to aid non-verbal communication** have been the use of **PECS through ipad applications** such as proloquo and gridplayer. These apps allow children who are non-verbal or who have limited speech to construct phrases using visual symbols with digital voiceover.

For **social interaction** use of software such as **matrix maker and online media** have been used to **create social stories** to help model social scenarios. Online games to facilitate turn taking and accessing audio mindfulness apps to regulate emotions were other examples.

5.3. Digital tools

5.3.1. Favourite applications in professional context

For the UK and Ireland, the following hardwire devices were cited (in order of popularity) :

- ipad/tablet
- Laptop
- Personal computer
- Whiteboard
- Projector
- ipod for music downloads

In terms of applications to download and play on hardware, the following were cited:

UK	Ireland
Microsoft Office (including excel, word and	Applications to facilitate communication through
publisher for visual resources)	PECS e.g.: Grace app
Video platforms e.g.: YouTube and BBC bitesize,	Applications to enhance academic skills in
TrueTube.	literacy and reading e.g.: phonics genius, starfall,
	clicker.
Online Education and problem solving	Applications to help develop fine motor
applications e.g.: Education City, Lightbot	coordination e.g.: Dexteria Junior
(programme skills), mindcraft	
Applications for classroom scheduling,	Software to create communication overlays and
organisation and recording of progress e.g.:	educational resources e.g. Matrix Maker
Evidence for Learning, Class Dojo	
Applications to facilitate communication through	Video Platforms e.g. YouTube
PECS e.g.: Proloquo	

5.3.2. Context and use of digital tool

In response to the question of ownership, all of digital tools alluded to by Irish respondents are owned solely by the Schools, with a mixture owned by both the school, the child and family for the UK. Most pivotal uses for digital tools revolve around greater communication (for both non-verbal and verbal students) and transparency in teaching as well as fostering development of academic skills (phonics, literacy and learning).

An example from a UK NAS school referred to the use of MyMaths and Read Write Inc applications on ipads that could be easily accessed at home to engage parents in the programmes as well as in school. Utilising applications for classroom organisation, presentation (e.g.: via interactive whiteboards) tracking progress and rewarding achievements.

For example a principal at an NAS school in the UK commented: 'Staff are able to access ipads to record and evidence progress and use Classroom Monitor to record and show these to parents at MYProgress meetings through the year. Staff also utilise celebratory pupils work and progress Apps called Trilby TV and See saw which utilise pictures or movie based evidence which is displayed around monitors in different parts of school. School can also electronically send examples of students work directly to parents in order that parents can join in the celebration and assessment of students work.'

Having a digital medium has proved useful for reducing anxiety when communicating needs for some students and well has providing a means to help circumvent poor handwriting.

A principal from an Irish mainstream school commented that 'As our school is very small in size and without access to a sensory room it very important for us to have equipment to help the child self-regulate his behaviours. With ipads the touchscreen removes the need for a mouse and keyboard which the child finds difficult to manage.'

Flexibility in customizing and **transferring data between platforms** (when professionals are confident) is also highlighted briefly as a potential benefit in the classroom, for example '*Turn taking can be targeted using the ipad, whiteboard, air server and other digital tools*' (Primary teacher in ASD unit, Ireland).

One NAS school in the UK cited the high benefits from the level of independence ipads provide through use of scheduling applications for daily organisation and pre-prepared mindmaps, which could be installed to help problem solve in daily situations. In the school environment the accessible controls and installed apps allow the student to work at their own pace with reduced pressure.

5.4. Technical difficulties of use

Most common technical problems described were *unreliability of wifi or internet connection*, that hardware (ipads, tablets) were *easy to break*, *short battery life* and *general malfunctions in hardware*.

Reliance on the IT department along with **lack of training with software** and incompatibility with old editions of software were also cited as *significant limitations*.

Some professionals commented that when using digital tools, it is 'Sometimes difficult to separate different functions' (Speech & Language Therapist, UK) and 'A lot of the time, staff working with pupils tend to use iPads as a reward/reinforcer rather than an educational tool due to not being comfortable with new technology' (Special educational needs teacher, UK).

Some professionals commented that it is sometimes *difficult to regulate use of ipads/tablets in educational settings*, as internet access is a distraction and children want to use for entertainment or special interests instead of school work.

Possible suggestions to remedy this included '*Having separate ipad/tablet which is colour coded for use* of communication only' (Speech & Language therapist, UK) and '*In order for the iPad to be used for* educational purposes a professional needed to supervise its use' (School teacher, Ireland)

Professionals also provided examples of some tricks or shortcuts that have implemented to facilitate easier use such as: *setting restrictions onto an ipad so only a single app can be accessed* and used at a time, *creating a watch list for YouTube to list the same videos again* and *recording video evidence of work*.