Profiling the communication of people who have visual impairment and additional disabilities:

Description

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This document and others associated with profiling the communication of people who have visual impairment and additional disabilities are available to download from my website at


A range of other articles is also available on other pages of the website.

The development of the profile is described in this document. However, I wish to take this opportunity to note that a previous version was in use at RNIB Pears Centre for Specialist Learning. As Lead Speech and Language Therapist there, I supported the speech and language therapists to use the profile and they made valuable contributions to this revised and improved version.

For further information about RNIB Pears Centre for Specialist Learning, go to www.rnib.org.uk/pearscentre

Please refer to this document by acknowledging the author, providing the web address and noting the date that you accessed the article.

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Introduction

Assessing the communication skills of children, young people and adults who have visual impairment and additional disabilities is a difficult task. Indeed, many people in this group remain at a very early developmental level and communicate in idiosyncratic ways. In practice, this means that assessment is really not feasible. It is, therefore, more appropriate to think in terms of profiling. The process set out here results in the production of a profile which describes how a person who has visual impairment and additional disabilities communicates functionally in everyday situations.

In itself, assessment or profiling is an empty process; to be meaningful and useful, it must provide some benefit to the person who has been assessed or profiled: it must lead to the person’s needs being properly addressed. With most assessment tools, that is a separate process. With the profile described here, it is an integral part of the process. This is because the profile not only describes the person’s current communication skills; it also specifies how other people can best support the person’s communication. It does so by describing the communication environment the person requires, including the communication means the person uses both receptively and expressively. For those in education, the profile also specifies the person’s current communication target(s) and the strategies for achieving them. In this way it supports the promotion of further communication skills. It is therefore important that the profile is made available to all those concerned with the person: both the family and practitioners.

Some formal assessment can be appropriate for the more able people within the group. It is possible to report the findings of formal assessment in the profile and incorporate them in the description it provides.

The profile reflects the current situation for the person and should be updated periodically to take account of changes in the person’s skills and needs. Previous profiles should be retained to provide a record of changes over time.

The profile provides information only about the skills and behaviours the person displays; absent skills and behaviours are omitted. It is thus a positive document, focussing on abilities rather than disabilities.
Those intending to compile a Profile should read the document “Profiling the communication of people who have visual impairment and additional disabilities: Guidelines for use”.¹ You are also strongly advised to read the remainder of this article.

**People who have visual impairment and additional disabilities: terminology**

One of the difficulties faced by those who work with people who have disabilities is that of labelling. Labels are, in many ways, unpleasant and they can sometimes obscure an individual’s real strengths and attributes. But if practitioners are to adequately address the needs of people who have disabilities, labelling seems to be unavoidable. With regard to labelling, one difficulty is fashion; a label that is in common use in one period is replaced a few years later, often to be viewed with contempt.

The people who are the focus of attention here are complex, and this complexity is reflected in labelling them. “Visual impairment”, the term used here, is not ideal, as it encompasses a wide range of visual ability, and there can be significant differences between being totally blind and having even a very little sight. However, alternatives to visual impairment present problems: for example, “blindness and partial sight” is rather more clumsy; “sight loss” implies the person was born sighted and then lost his / her sight, which is not the case for most of the people we are concerned with here. Including a person’s other needs in the label is also difficult. In the recent past a variety of labels has been employed, including “multiple disability and visual impairment (MDVI)”, “visual impairment and complex needs” and “visual impairment and additional disabilities”. All are cumbersome and inadequate; “visual impairment and additional disabilities” is used here as it seems to be the best reasonably short label.

When I was developing the profile, I intended it for use with children. “Young people” was not then used to describe older children; this

¹ This article is available at [http://ianpbell.wordpress.com/profiling-the-communication-of-people-who-have-visual-impairment-and-additional-disabilities/](http://ianpbell.wordpress.com/profiling-the-communication-of-people-who-have-visual-impairment-and-additional-disabilities/).
simplified matters. Several years after first developing the profile I used it with young adults in further education. This made me aware that it was no longer appropriate to describe the profile as being for children. Therefore, rather than using “children, young people and adults who have visual impairment and additional disabilities”, I now use “people who have visual impairment and additional disabilities”. In places, for stylistic reasons, I slightly abbreviate this to “people with visual impairment and additional disabilities”.

Labelling can be offensive and some people have very strong preferences in this regard. Readers are assured that no offense is intended in any of the terms used here. I fully recognise that each person is unique, with his or her own range of difficulties, skills and attributes. As far as communication is concerned, I believe it is essential to describe those difficulties, skills and attributes as fully as possible. That is the motivation for this profile.

**People who have visual impairment and additional disabilities: general characteristics**

The profile is designed for use with people of all ages who have visual impairment and additional disabilities. The general characteristics of these people vary widely; there is no such thing as the typical person within the group.

In addition to visual impairment a person in this group is likely to have some degree of learning disability. In many people this is severe or profound. Additional disabilities include

- severe motor disability (e.g. cerebral palsy)
- hearing impairment
- epilepsy
- autism
- severe feeding difficulties
- chronic, severe medical conditions.
People who have visual impairment and additional disabilities are likely to have cortical visual impairment (CVI) in addition to their optical visual impairment.²

Most, if not all, people with visual impairment and additional disabilities have significant communication difficulties and many are at developmentally early stages. Many people in this group communicate in idiosyncratic ways; in order to communicate successfully, they rely very heavily on sensitive people who know them extremely well.

A description of the profile

To take account of the communication skills and needs of people who have visual impairment and additional disabilities, the profile covers the early stages of communication development, extending into early symbolic communication.

The profile cannot be purchased: it is freely available online.³ The document consists of a template which guides the user through the process of compiling a profile. The template consists of a menu. When working through the menu, the compiler

- omits items which do not apply to the person whose profile is being compiled
- personalises items so the full profile provides a unique description of the person
- is free to add other items not provided in the menu
- can amend the sequence in which items are presented.

² This is not the place to explain CVI. For a general introduction to CVI (also referred to as cerebral visual impairment) readers are referred to a section of the Scottish Sensory Centre website which contains several articles on CVI and on brain / neurological causes of visual impairment. See, e.g. Blaikie (no date) in the References to this article.

³ Go to http://ianpbell.wordpress.com/profiling-the-communication-of-people-who-have-visual-impairment-and-additional-disabilities/
The menu is therefore very adaptable. Because items can be added, the user is free to extend the profile beyond the stages of development covered. Thus the menu can be used to compile a profile of someone who has skills which are more advanced than those which appear in the menu. Extending the profile in this way requires specialist knowledge of communication development in individuals who are visually impaired.

Communication is a very complex area of human behaviour, meaning that a person’s profile can run to several pages. However, a very brief profile could gloss over much that is important; there is a danger it would be of no real use in guiding facilitation or monitoring progress. If the compiler is concerned that a person’s profile will be over-long, he/she can omit whole sections in order to focus on the most important features for that person.

As the profile is intended to describe the person’s communication skills and related behaviours, it gives information only about the skills and behaviours the person displays; absent skills and behaviours are omitted. This ensures that the profile is expressed in positive terms, a particularly important attribute from the point of view of family members. Many people with severe visual impairment and additional disabilities have limited skills. A conventional tick-list would provide a very negative description. This is because it would contain crosses or blanks, rather than ticks, against many (perhaps most) items. Although it is important to know what a person cannot do when planning facilitation, this information can be obtained by referring to skills not included in the completed profile, and from any existing formal assessment reports. Omitting absent skills and behaviours not only ensures the profile is positive, it also keeps the profile as brief as possible.

The version of the profile described here is rather different from the original profile. Whilst using the profile for several years, I made many modifications. It was then published (Bell, 2008). Since then many further modifications have been made. In preparing the current version, I considered adapting items to include information about

- how frequently the person uses the skill or displays the behaviour
- the person’s level of competence.
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Such information is a feature of some published tools. A case in point is the *Talkabout Social Skills Assessment* (Kelly, 1997). Assessors who use this tool rate the person on each item (e.g. Eye contact, Use of facial expression, Use of gestures) as *Never good / Not very good / Quite good / Very good*. However, although Kelly expands on the meaning of these ratings, making decisions of this kind is very subjective. Also, there is no scope to provide additional information. For example, in the section on eye contact, *Quite good* is defined as “Some appropriate use of eye contact, e.g. when under stress”. It would be useful to have the facility to expand on this, describing what causes the person to become stressed and so to use eye contact, and giving some indication of the level of stress involved. It was decided not to adopt Kelly’s approach here.

Victoria School in Birmingham uses another format for describing how well established a skill is (Murdoch, 2009). For each skill / behaviour, the assessor records the dates when the child

- *is aware* (i.e. is ready to learn the skill / behaviour in question)
- *consistently uses the skill / behaviour in some but not all of the situations in which it could be used*
- *consistently uses the skill / behaviour in all appropriate situations, although he / she may need prompting in unfamiliar settings or activities*.

However, this approach does not seem readily applicable to communication skills / behaviours. For example, concerning expressive communication, how can someone determine the situations in which it is appropriate for another person to request a drink? Only the person him or herself knows when he / she wants a drink. Just because a person does not request a drink in some situations, does not necessarily mean that the ability to request a drink has not been generalised. In addition, it seems to be inappropriate to think in terms of people being aware of, or ready to acquire, an expressive skill. It was decided not to adopt the Victoria School approach for here.

In the *Pre-Verbal Communication Schedule* (Kiernan and Reid, 1987) three “scoring” approaches are used:

- *Yes / No*
- *Usually / Rarely / Never*
- by recording the number of correct responses.
All three forms of “scoring” present problems. In fact, the use of “score” is seen here as problematic because it implies that assessing communication can be reduced to a numerical value.

Yes / No seems to be inadequate for at least some of the items “scored” in this way. For example, in the section on Needs and Preferences, item 3 is Does the student enjoy spending time with other people, e.g. playing a game, being held, being sung to, looking at pictures or books? Although a space is provided to record Other needs and preferences, this does not allow properly for comments on the individual parts of the item itself. This may be important, as a person may:

- enjoy playing a game with one or two key people, but not with anyone else
- be too big to be held, and past the age when this is appropriate
- have absolute pitch and like having songs sung by people who can sing in tune, but find it aversive when people sing out of tune
- like looking at very large pictures of trains, but no other pictures or books.

Many of the people for whom the profile is intended are complex and difficult to communicate with; they deserve a very detailed approach to assessment which provides the user with opportunities to compile a very detailed, comprehensive description. Yes / No responses to fixed items do not permit this.

There are also difficulties with the Usually / Rarely / Never approach. This is because many people with complex needs vary markedly over time and settings. In addition, deciding how to “score” using this approach is heavily subjective. Furthermore, it is inadvisable to state that a person who has visual impairment and additional disabilities “never” uses a particular skill. Although it may be the case that the person has never been observed using that skill, this may be chance – had the person been observed on other occasions, or in other settings, or with other communicative partners, he / she may have used the skill several times. The use of the word “never” also means describing the person in a negative way. This is seen as unhelpful, as it can emphasise just how disabled the person is. This may be very unpleasant for family members, and may result in the lowering of expectations on their part and that of practitioners.
Although scoring an item in terms of the number of correct responses appears to be objective and reliable, because of the variability of many people who have visual impairment and additional disabilities, it is possible a person would score 3 out of 3 on one day, but zero the next day. Scores of this kind are really not very helpful.

In fact, the person compiling a profile using the process described here personalises each item in the profile. Therefore, he / she can easily refer to how frequently the person displays any particular behaviour or uses any particular skill. This can be illustrated using an item from Section 8 which deals with how the person responds to and participates in music, songs, stories and poems. In the menu, this item reads

I spontaneously join in with some music / songs; e.g. I bang on the table / clap / rock / sway / vocalise / use a simple musical instrument. I do this when I hear … …

The item can be re-written in order to comment on how frequently the person displays the behaviour:

I often spontaneously join in with lively folk-dance music; e.g. I often bang on the table; also, I have just begun to clap occasionally to this kind of music; I do not bang or clap in time to the music.

Profile items can also be re-written in order to comment on the person’s level of competence. In fact, the re-written example above includes such information as it states the person does not bang or clap in time to the music.

Although compilers should personalise items and, when appropriate, include information about frequency and competence, they should bear in mind that there is a danger of including so much information that the profile becomes unwieldy: a huge document may not be used.

The profile is expressed in the first person, as if it has been written by the person him / herself. This serves as a reminder that the individual under consideration is a person who deserves to have his / her abilities and needs acknowledged and dignity respected.

Experience shows that most people who have severe communication disabilities display different communication skills in different settings. A person’s profile should therefore be seen as applying only to the setting...
in which it was compiled. There is no reason why a person should not have a profile for each of the significant overall settings he / she regularly experiences (e.g. the family home, school / college, residential home, etc.). However, this may not be practicable, and it may be helpful to adapt individual items to reflect differences across different settings. This can be illustrated using an item from Section 6 which deals with how the person communicates in different situations. In the menu, this item reads

It is easier for me to communicate at some times of the day than at others. I communicate best at … …

The item can be re-written thus:

It is easier for me to communicate at some times of the day than at others. At home, I communicate best in the evening, when I'm relaxed after my bath, but before I go to bed. However, in school, I communicate best at snack time.

Examples of completed profiles and commentaries are provided in separate documents.

The profile sections
Since the profile was first published, the number of sections has expanded. Whereas there were previously six, there are now 12 main sections, some of which are subdivided. The sections are:
1. The main changes in my profile since the last version. (This provides an opportunity to record progress.)
2. My current communication targets and plan
3. The communication environment I require
4. A general description of my communication skills, including information on intentional communication
5. My attention skills
6. How I communicate in different situations
7. How I interact with other people
8. How I respond to and participate in music, songs, stories and poems
9. How I participate in conversations with other people
10. What I understand
11. The meanings I communicate and how I communicate them
12. Making choices.
The profile was designed as a result of practical experience. It was gratifying when subsequent reading (Coggins, 1998; Crais and Calculator, 1998; Eyre, 2000; Kublin et al., 1998; Pease, 2000) revealed that the principles adopted were being recommended by respected practitioners and researchers. For example, these authors recommend assessing children in everyday settings, while participating in daily routines, and including other significant people in the process.

In drawing up the profile, reference was made to numerous sources on the acquisition of communication in babies and infants. The Checklist of Communicative Competence (0–2 Years) (Gerard, 1986) and The Early Communication Assessment (ECA) (Coupe O’Kane and Goldbart, 1998) were particularly valuable, especially when sequencing the items in Sections 11 and 12. Use was also made of work by Ware (2003) with regard to the difficulties people have interpreting the behaviour of children with multiple disabilities. These can arise from the child’s delayed and idiosyncratic responses, for example.

The need for the Profile

In order to set targets for any person and to record and monitor progress, it is essential to have a clear picture of that person’s skills. However, assessing communication in people with severe visual impairment is very difficult. This is particularly true of those who are at developmentally very early stages and have additional disabilities. There are several reasons for this, as described in the following paragraphs.

Assessments for the sighted are not suitable for assessing those with severe visual impairment, as the outcomes or scoring may be misleading. The nature of the tasks changes for an individual with little or no sight because additional demands are being made. For example, in young sighted children communication is sometimes assessed in part by presenting them with several everyday objects laid out on a table or the floor. The child is asked to identify named items (e.g. Show me the cup; Where’s the ball?; Find Teddy). For a child with no sight, the task is very different: for example, the child will:
• need to use tactile scanning of the display, which is less efficient than visual scanning
• have to hold in mind the name of the required item for much longer than the sighted child
• need to remember where items are located or will have to search afresh for each item
• risk inadvertently moving items, and may have difficulty re-locating them.

Brambring (1992) likens the task for the totally blind child to that of placing items in different rooms of the house for the sighted child.

Even for a child with a little sight, the task is different: for example, although the child may be able to search visually, this will take longer, be more tiring and place greater demands on the memory. In addition, children with severe visual impairment do not acquire symbolic understanding in the same way as sighted children, so toy items (e.g. a toy car) may well be meaningless.

Few assessments are designed to assess communication in children with visual impairment, and fewer still in children with visual impairment and additional disabilities. Most of those that do exist have serious flaws, particularly for children with impaired motor function. I am not aware of any assessments designed specifically for adults with visual impairment and additional disabilities, or of any published assessments for children or adults who have both visual impairment and an autism spectrum condition. (In relation to children who have both visual impairment and autism, it is worth noting that development work is being undertaken on the Visual Impairment and Social Communication Schedule (VISS) (Absoud et al., 2011).)

People who have visual impairment and additional disabilities interact and communicate in idiosyncratic ways; published assessment tools do not reflect this.

The need for the assessor to learn about the person as an active, expressive communicator is seen as crucial. Unfortunately, published assessments tend to place the person being assessed in respondent roles, and generally focus on receptive skills. When expressive skills are assessed, this tends to be in contrived situations. Tests provide little or
no information about how the person communicates functionally in everyday situations. They disregard the fact that the person does not communicate alone, but with communicative partners, who play an essential role in interpreting the person’s behaviour.

Published assessments provide information only about what the person did at the time of assessment. However, many people who have severe visual impairment and additional disabilities vary markedly from day to day with regard to the skills they display. It is therefore important to gather information over a much longer period of time to establish a reliable skill profile.

Developing the Profile

I originally developed the Profile in the late 1990s when I was the speech and language therapist in a small day and residential school for children who had severe visual impairment and additional disabilities. The school has since closed. At that time, I did not consider publishing the Profile.

However, around that time I ran several two-day courses on the communication of children with severe visual impairment. These courses were attended by teachers, teaching assistants, parents, speech and language therapists, residential care workers, educational psychologists and doctors. Once the value of the Profile had been established through regular use at the school, reference was made to it during these courses. Course participants typically expressed an interest in the Profile. Informal feedback, in the form of participants’ verbal comments, suggested the Profile was viewed favourably. A further indication that publication might be appropriate came in the form of an enquiry about the Profile from a speech and language therapist: she had seen an unpublished version and asked where she could obtain it.

Having developed and used the Profile with children who had visual impairment and additional disabilities, I later worked for some years with children and young people who had autistic spectrum conditions. I modified the Profile for use with this group of people. In the light of experience with that version, minor changes were made to the Profile I had originally developed. It was at this time that the Profile was published (Bell, 2008).
Additional, more substantial, revisions have been made since. Some of these arose from the experience I gained when I worked with young adults in a specialist further education college. The people I supported had learning disabilities, in most cases in conjunction with a range of additional disabilities, including visual impairment. Some of the students had visual impairment in combination with autism.

Having made a range of significant revisions, I felt it was important to revise the published version. Subsequently this became more urgent when the published version became unavailable.

By this time, I was providing clinical support to the speech and language therapists working at RNIB Pears Centre for Specialist Learning. This is a school and children’s home for young people with visual impairment and complex needs. Many of these young people have autism in combination with visual impairment. The speech and language therapists in this centre were using the Profile. I therefore embarked on a thorough revision, taking account of the valuable feedback provided by my colleagues. The revised version was then trialled for a few months and a few further modifications were made.

Other resources

The Profile is similar in some ways to the ‘Personal Communication Passport’ concept (Millar and Aitken, 2003). However, there are significant differences. The Profile is part of the process of assessing the person's communication skills, and is intended primarily to provide a comprehensive description of the individual’s skills. In contrast, the Personal Communication Passport is intended (amongst other things) to facilitate effective communication between the individual and other people. The Profile deals only with communication, describing in detail the person’s skills. The Personal Communication Passport provides information about a wider range of aspects of the person’s life. For people in education, the Profile should be used to support target-setting, with links to the IEP, Care Plan or similar, whereas the Personal Communication Passport is more informal, is not a target setting tool, and does not necessarily have links with the IEP or Care Plan.

4 Go to www.rnib.org.uk/pearscentre.
The two resources are not incompatible; indeed, the Profile can be a very useful means of obtaining information about a person’s communication when compiling his / her Personal Communication Passport.

Another important recent resource is the *Developmental Journal for Babies and Children with Visual Impairment* (Department for Education and Skills (DfES), 2006). It is designed to help families track and understand development in their child in five areas:

- Social and emotional development
- Communication, language and meaning
- Play and learning
- Movement and mobility
- Towards independent self-care.

Like the Profile, the Developmental Journal supports the sharing of information between families and professionals.

The Developmental Journal was not developed primarily for use with children who have visual impairment and additional disabilities, or, of course, for use with such adults.

Some concern has been expressed that it might be emotionally difficult for parents of children who have visual impairment and additional disabilities to use the Journal. This is because parents would be unable to record more than a few skills as established, reminding them very clearly just how limited their child’s skills are (Bell, 2007). One of the aims when developing the Profile was to avoid this, and to express as much information as possible in positive terms.

Another feature of the Developmental Journal is that it does not include behaviours characteristic of many individuals with additional disabilities. For example, many such people are much less physically or vocally active than a typically developing infant. Thus, there are fewer behaviours to which caregivers and practitioners can respond. Paradoxically, other individuals are much more active, meaning they are rarely at rest or silent; this also makes it hard for caregivers and practitioners to respond, as the person leaves few gaps in which a response can be made. Indeed, some individuals fluctuate between
doing very little and doing a great deal. The Profile includes items dealing with this.

Again, the Developmental Journal and the Profile are not seen as incompatible. If the Developmental Journal has been used with a preschool child, it could be helpful when the child first enters school. Experience shows that most children communicate differently in the two environments of home and school. Many children seem to communicate more effectively and more frequently at home, where they have very close relationships with people who are very important to them, and where objects, events and routines are very familiar. The Developmental Journal and the Profile compiled when the child first enters school may show that the child is communicating more effectively and more frequently at home than at school. If so, this information could be helpful when selecting the first targets to be put in place in school: it might be most appropriate to generalise skills already established at home into the school setting.

**Additional benefits resulting from the use of the Profile**

It is accepted that profiling an individual in this way is very time-consuming. Many practitioners may feel that they simply do not have the time. However, people who have visual impairment and additional disabilities cannot be properly assessed quickly and easily. As stated earlier, communication is a very complex area of human behaviour. It plays such a central role in so many aspects of life that it is essential to have as clear a picture as possible of each individual’s skills in this area. If we are to adequately address the needs of people who have visual impairment and additional disabilities, we have to accept the requirement to devote a considerable amount of time to assessing their communication skills.

In the school in which the Profile was first developed, its use brought several unforeseen benefits. It provided a forum for the discussion of communication skills, encouraging staff development in several ways by:
enabling staff to develop a better understanding of the individual’s abilities

helping staff to understand more fully what communication is and how it develops

raising the self-esteem of staff by making them aware that they were often already effective when interacting and communicating with the individual, and promoting the acquisition of further communication skills

enabling staff to identify how they could develop their own skills to become even more skilled at working with communication

helping staff to anticipate which skills the child might acquire next, enabling them to contribute more effectively to the target setting process.

Perhaps the most important additional benefit was that it resulted in a team approach with everyone contributing. It became easier for everyone to see that communication is a matter for all staff, not just the speech and language therapist. Colleagues also developed a much better understanding of the fact that communication is important at all times, in all situations. These were enormous benefits and, in themselves, made the initial investment of time in developing the Profile very worthwhile.

Concluding remarks

Profiling the communication of people who have visual impairment and additional disabilities using the procedure described here is very time-consuming. It is recognised that busy people may believe they simply do not have the time to adopt this approach. I believe that is a mistaken belief. This is because the profile provides a description of a person’s communication skills which is

- personalised
- truly comprehensive
- detailed
- positive.
So, although using the procedure described here is time-consuming in the first instance, it results in a very high quality profile that provides a clear specification of

- the communicative environment the person requires
- the means of communication other people should use to support the person’s understanding
- the means of communication other people should support the person to use when communicating expressively.

It also supports the specification of one or more targets for facilitating new skills.

Ultimately, therefore, it may actually save time.
References

Website accessed 2nd January 2013


Bell, J. (2007) Personal communication, reporting a discussion at an RNIB Focus Group Meeting for Professionals Working with Children with Complex Needs and Visual Impairment at Penn Hall School, Wolverhampton (28 November)

Websites accessed 2nd January 2013


Website accessed 2nd January 2013


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Ware, J. (2003) Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties. London: David Fulton