

**NHS England Accessible Information Standard Pilot Study Berkshire  
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**Background to pilot**

This document summarises how we have been modifying our practice to ensure that we maximise patient engagement and involvement through appropriate information provision. This work started through direct clinic practice and over time evolved into the creation of an 'Information Pathway' and a number of novel approaches and models.

This report includes both work undertaken specifically during the trial period and preceding this frame. It also refers to related developments that are summarised below. This will include qualitative data comprising case studies and limited quantitative data before closing with lessons learned and implications for future practice and information planning.

**Key developments:**

These developments arose out of 5 years work looking at ways of making information accessible to people with learning disabilities principally using Computer Aided Information (CADI) – Process by which a voice output communication aid is used to provide information where people are unable to read. This includes the use of relevant multi-media including video and/or music. This approach was developed due to the poor to non-existent literacy skills of people with learning disabilities.

- Information pathway (*publication a*) – a process that can be used to inform the process of information provision. Crucially this to include a process of target setting and review to evaluate success – copy in appendix.
- Information Passport – The document that can be used to summarise key requirements that can support adequate provision and the record of previous targets. To include key details: sensory; physical literacy and other cognitive needs. This document aims to be shared digitally - copy in appendix.

- Information Targets – including: prioritised information for each a patient and details as to what the person may need to be supported to understand- not just new topic information but also its meaning as required.
- Information Guardians – where the individual is not able to be supported to access information independently – a range of people who can also support the individual. These people must be included in any information plan and details be included in the passport.

These development highlight areas discussed within the draft accessible information standard and dovetail into the standard.

### **Examples of evidence base for the approach - Qualitative case studies: -**

Selected examples of work we have undertaken aiming to show variety of strategies used. Several case studies have been published in peer review journals and the relevant publication is cited in text where this has happened.

#### ***Role – using strategies to primarily support the individual patient:***

##### **1) Mr A (publication b):**

*Screening revealed:* sound understanding of spoken language and grammar but struggled with pronouns. He required specific implications of facts and elements to be made clear. He was profoundly blind and unable to read text but was able to access switches.

*Information required / challenges* – tenancy agreement – A one off piece of work. It was considered that Mr A would be able to understand all elements of his tenancy – targets were set and a period of review agreed.

*Format selected and modifications made:* Computer was accessed via switches and auditory scanning to accommodate his access needs (spoken prompts). Small scale trial was undertaken to promote his use of switches which showed the support how to vary the switches to help him retain their specific function in the program

*Outcome* – at review Mr A was able to understand the information and he signed a tenancy agreement.

##### **2) Ms B (publication c)**

*Screening revealed* – she was unable to read, needed support to understand complex information and to follow sequences of events

*Information required / challenges* – Ongoing and evolving information needs – initially information regarding pregnancy and later regarding child care looking at both practical care tasks, child development, play activities and finally child protection and adoption procedures,

*Outcome* – increased awareness of how to play with her daughter, increased understanding of child protection procedures and awareness of what would happen regarding adoption.

##### **3) Ms C**

*Screening revealed* – has some literacy skills if information written in easy read form and sentences kept concrete and simple English, difficulties in organising information so that she could understand it and find information she required when she needed it.

*Information required* – child protection procedures regarding foster care.

*Outcome* – 1:1 session with Ms C reviewing the information each time with new information within pre-organised file using pictures as reference/categorisation of information.

#### 4) **Mr D (publication d)**

*Screening revealed* – limited literacy skills mainly single words, verbal language needed to be in short sentences and reasonably simple language. He had difficulties in having structure to enable decision making.

*Information required* – initially looked at practical daily task e.g. dressing using computer programme to guide Mr M through the process. Once he was able to use and understand the programme developed it to cover a wider range of problems which he would encounter in his life e.g. support workers not turning up, housing emergencies, phoning in sick to work.

*Outcomes:* Mr D appeared to have more confidence concerns decision making.

#### 5) **Ms E**

*Screening revealed* – no functional literacy and language comprehension limited to everyday words – uncertain with negatives and pronouns. Had awareness of photographs but no symbols – needed access to spoken language. Short sentences most effective – benefited from social stories to explain everyday situations.

*Information required / challenges* – explanation of use of sanitary towels during her period. There was a specific focus on the sequence of actions around their use. A Talking Photograph Album was used to explain basic sequence regarding use of towels and their safe disposal. The staff were training as Information Guardians in order to remind and prompt use of talking photograph album as required

*Outcomes* – her behaviour changed and she was able to use sanitary towels and access the community during her period. Talking album was left with staff as reminder and support.

***Role – educating Information Guardians as primary function because the patient is not able to independently access, understand, retain and/or interpret information.***

#### 1) **Mr O**

*Screening revealed* – Good understanding of single words and basic grammar. He finds it very hard to use reasoning skills to make sense of information. No functional literacy skills

*Information needs/challenges* – Relating old experience to current situations.

*Strategies* – Staff trained and supported to ask guided questions and use prompt to help Mr O link new and old information and promote understanding in the here and now. This is likely to happen regularly as he needs repetition of previous experiences when in similar situation in immediate future.

*Outcome measures* – ongoing support likely to be required to continue to meet his needs. Careful support in situation can have positive outcome at that moment.

## Pilot study

### 1. Scope and scale of the pilot

The pilot study was based within community team for people with learning disabilities (CTPLD). The pilot looked at referrals regarding accessible information to Occupational Therapy and Speech and Language therapy between February to March 2015 within CTPLD.

Referrals – 2 individuals

7 within group setting

The pilot used accessible information pathway (see diagram 1) as pro forma for process to look at process of developing and providing accessible information.

### 2. Actions taken to effectively implement or trial the standard in existing systems

The table below gives details of the interventions used

1 Stage Referral	Referral What kind of information needs to be made accessible e.g. narrative, instructive, guidance, questioning, interactive	1 – assertiveness skills 1 – moving house 7 – recipes within cookery group setting
2 Stage Assessment	Language screen – SLT assessment	4 - No SLT assessment 5 – SLT assessment within the past 5 years
	What physical access is achievable e.g. vision, motor skills	9 – no physical access difficulties
	Literacy screen Is the person able to read?	3- yes 5 – no 1 – not known
	Literacy screen 2 Can the person comprehend read text?	3- yes 5 – no 1 – not known
	Verbal reasoning screen	1 – screening undertaken 8 – not done
	Personal choice of format/approach – check with individual re options	2 – information given following consultation with individual or family 7 – group situation so all had same information offered
	Decide format	1 – written with individual 1- videos on You Tube – personal preferences 7 – written recipes used within group situation
3 Stage Creation	Examine information that needs to be made accessible:  What are the information targets?	1- assertiveness techniques 1- moving from family home and sharing a house 7 – how to cook X
	Devise format considering: text, pictures, layout, language used and organisation of materials.	9 – information made

	What medium to use? Consider access to the information/device	1- personal file held by individual 1 – had access to internet and you tube 7- written cookery recipes
	Does staff training need to be considered?	9 – not necessary in these circumstances
	Is information guardian required	5 – yes 4- no
	Role of guardian	Promoting choice with information -4 Accessing and focussing onto information (first session) – 1 Explaining and talking through - 5
Stage 4 Review and evaluate	Check information is accurate, and accessible	9- done
	Issue information to individual and/or carers	9 – done
	Review success of intervention/information Can information be understood and used functionally	1 – completed 8 – ongoing work
	Develop information passport	1- developed 1- draft 7 – ongoing work

Second theme involved liaison with the team managing the electronic health record (RiO) to negotiate for the information passport to be made an alert on the main screen for each patient to raise awareness and promote consistency of implementation and support.

### 3. Impact and cost of implementing and following the standard / aspects of the standard

The main impact of work making information accessible has been focused around staff hours.

#### **Prior to pilot work described within case studies:**

Case studies:

Assessment	8 hours approx
Preparation	17 hours approx
1:1 sessions with people to learn and develop skills	16 hours approx
Total	41 hours approx

NB case studies are examples and representative of previous work the hours totals given are a rough estimation to indicate time commitment required.

Staff training prior to pilot work

Development of training packages	20 hours
Staff training sessions	21 hours
Total	41 hours

#### **Pilot study:**

Development time for accessible information pathway and information passport within pilot study – 5 hours

## Interventions/work

	Assessment *	Preparation	Sessions to develop skills	Information passport
Individual cases	2 hours	4 hours **	1 hour <sup>2</sup>	1 hour <sup>a</sup>
Group cases	6 hours	12 hours <sup>1</sup>	9 hours <sup>3</sup>	Not done as yet for group members

\* all assessments noted within pilot study had been done within the previous 5 years and were not done during the study period due to lack of Speech and language therapy (SLT) staffing at the time. At least one person within the pilot study requires an up to date SLT assessment

\*\* One of the individuals made their information with the OT so there was no actual preparation time

<sup>1</sup> this was the session making the information for the individual described above, the second individual's work is ongoing and as yet there has not been feedback regarding how successful the information provided has been.

<sup>2</sup> This was on a weekly basis by student OT to devise easy read recipes for group sessions

<sup>3</sup> Actual cookery group sessions where recipes were followed to prepared midday meal.

<sup>a</sup> One passport has been completed and the second is in draft form as awaiting updated SLT assessment

The main cost implication has been around staff time to prepare information and for paperwork.

## 4. Feedback on the practicality of implementing the standard using existing documents / in its current form

The pilot study and previous case studies illustrate that making information truly accessible to people with learning disabilities following the principles of the standard, is time consuming especially in preparation and in passing on the information to ensure that it is effective. This does form a conflict with other staff commitments and priorities within clinical work and practice and raises the requirement to consider strategically how to ensure that a realistic process is put into place by which work can be undertaken. However, having clinical staff work with people in the process of creating their information improves ownership of materials, supports involvement in the process and increases the chance that it meets the individual's needs and will be of use to them. The benefits of ensuring that people have information they understand are outlined below but long term if people are able to form informed decisions and choices regarding health and are enabled to live healthier lives this will have a long term benefit for them and on the health service.

Efforts were made to generalise the skills required to develop CADI programs and understand some novel theories via the creation of staff training sessions that were held with professional staff at CTPLD and with relevant advocacy agencies. It intended to encourage other people to adopt the principals but was not effective in this goal. The software has recently been updated making the bulk of this material obsolete.

At a practical level ensuring access to hardware was a challenge. We were fortunate that Social Care was able to purchase a number of tough book lap tops which could be used to run the

software for CADI. Computers were loaned to people for specific pieces of work. This meant that they were not always able to access the resources and has led us to consider that a move to a virtual resource would overcome many of these issues.

There is ongoing negotiation with RiO (electronic notes system used within Trust) re putting the information passport onto the health notes system. Information passport content would be identifiable by an alert logo thus enabling relevant information to be shared by professionals promoting consistency within the organisation. It would remain a challenge to share this information with other systems that would include GP, Acute Hospital and other Rio systems.

Ensuring all relevant patients have adequate and appropriate screening of information which is reviewed as required. This is the basis of the 'Information Passport' and its completion would place significant strain of clinical resource that are not in place to provide this with current staffing levels. A mechanism to share existing knowledge (e.g. from education records where relevant) and undertake screening must be recognised and considered. Any ability to share resources between NHS organisations would support this objective.

The case studies at the start of this document highlight some of the innovative solutions that have been identified. This suggests the need to:

- Have a structure that would allow professionals to share ideas and practice – the use of a conference based system or virtual hub would be useful here. The establishment of a Multi-agency Special Interest Group could also be considered including representation of relevant clinical groups and carers.
- Ensure that all professionals have access to a range of different resources – not solely easy read that can be tailored to individual patient needs.
- Staff training and awareness building sessions must be undertaken to show what can be done
- GP commissioners must be made aware of the time and resource implications if we are to make information as accessible as it can be for a variety of clinical groups and individuals.

## **5. Benefits associated with implementing / following the standard**

- People should receive the right information at the right level for their communication skills and that will meet their needs. This should assist in:
  - Reducing anxiety
  - Increase ability to make choices e.g. re health needs, where they wish to live, what they wish to eat
  - Increasing skills e.g. use of recipes when at home, enabling personal growth (assertiveness skills)
  - Increasing individual's knowledge re what could happen e.g. child protection procedures and empowering them within difficult circumstances
- Having the right information means that people have their human rights met as outlined in the UN Convention on the rights of Persons with Disabilities 2009.
- Having the standard will hopefully direct senior management within the NHS to acknowledge that providing information at the correct level and using the right medium will enable people to fully participate in their health care. However it also needs to be acknowledged that one size

does not fit all and there needs to be flexibility within services to ensure that each individual's needs can be addressed. This would mean that clinical staff should be involved in the provision of information when and where necessary and the design and creation of information not left to communications teams/departments.

## 6. Any other comments

There were some challenges within this pilot study due to work pressures and staff shortages – both SLT and OT were understaffed during the process. However the honing of the accessible information pathway and the development and trial of information passport were positive outcomes.

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## References

### Publication a

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### Publication b

Waight M & Oldreive W - 2011 – *Supporting and enabling a blind adult with learning disabilities to sign a tenancy agreement* – British Journal of Learning Disabilities – Online April 2011 – April 2012 in paper

### Publication c

Oldreive W & Waight M – 2012 - *Information - Need it but can't read it: The use of Computer Aided Information* – Communication Matters – Vol 26 (1) pp34-36

### Publication d

Oldreive W, Moore N & Waight M – 2012 - *Steps to Independence – Supporting every day decision making with computers* – Journal of Assistive Technology – Vol 6 (1) pp 53-62