The evolution of an innovation; the Communication Profile - Learning and Innovation go hand in hand

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ABSTRACT
Practitioners in the National Deaf Child and Adolescent Service (NDCAMHS) have worked collaboratively to develop training, systems and practice to enable the use of Communication Profiles. The communication and language needs of children, young people and their families are observed in order to support the understanding of their impact on the mental health presentation of the person referred. This article describes the process of development which has enabled our teams to gain skills and knowledge. In addition, we identify areas for future work linked to language and communication for deaf young people and their families that have been highlighted by this process and the use of Communication Profiles.

KEYWORDS
Communication profiles; child mental health; deaf children; language; communication.

Background
The National Deaf Child and Adolescent Mental Health Service (NDCAMHS) was established in 2009 following a pilot from 2004 to 2009 involving services in London, York and Dudley. A fourth centre was added in Taunton in 2009 to enable full geographical coverage. The aim of the service is to provide community and in-patient mental health services for deaf children, hearing children born to deaf parents, and their families who are unable to access local mental health services. Often, with the families we work with, understanding communication and language is initially one of the key issues.
There are many families who have multi-lingual households, for example, English, British Sign Language (BSL), and Punjabi. It is also understood that linguistic skills in BSL sometimes vary due to lack of exposure to natural BSL or limited education. This has an impact on the families’ shared language; as a consequence communication and negotiations can be fraught. There is lots of information widely available about child development; parenting and mental wellbeing in written English and these are frequently inaccessible in other languages such as BSL. Therefore some deaf people are excluded from accessing these services and resources.

As a national Deaf CAMHS service, the staffing reflects the multi-disciplines needed for the holistic formulation of a child, adolescent and families’ needs, these may include; psychiatrist, psychologist, mental health nurse, deaf service consultant, specialist deaf outreach worker (SDOW), family support worker (FSW), child mental health worker (CMHW), occupational therapist, speech and language therapist and BSL/English Interpreter. All staff have experience of working with deaf families.

Since we are a relatively new national service, working groups focus on different aspects of service development. The language and communication working group meets quarterly. In order for us to understand the families we work with, with particular regard to their language and communication needs, we have developed the Communication Profile in order to inform our practice. The Communication Profile also acts as a language screening tool to highlight any further linguistic assessment needed.

As practitioners working within the service we strive to understand the impact of language and communication has on the mental wellbeing of deaf young people, especially lack of access. We also need to understand the background to communication profiling. We give a brief overview of these topics.

**Language, Deaf children and Mental Health**

Deaf children are more vulnerable to mental health problems than their hearing peers, with language and communication as the main contributing factors for this, other studies have shown that lack of language has a direct impact on a child’s mental health. These studies consider the impact of parental language, educational placement, language choice and audiological management. From such studies, it is clear that the context of a child’s developing language and communication has an impact on their mental wellbeing.

The key risk factors identified were early language deprivation, central nervous system disorders associated with the cause of the child’s deafness and increased risk of abuse. More recently a literature summary of the brain and language development discussed the links to emotional and behavioural difficulties for deaf children. It highlighted the complications of diagnosing developmental disorders in this client group if language and communication issues are not considered in detail.

The language and communication a child is exposed to in their early years will impact on how their brain develops and which skills they are able to use in later life, including inhibiting behaviours, focusing on tasks, and poor response to facial expressions.

For families where BSL is established as a language early on, the challenges faced are regarding accessing services rather than developmental delay. A recent report recorded that 62% of health care appointments went ahead without an interpreter, therefore when working with deaf children it is essential that clinicians are sensitive to their clients communication needs and if necessary use a British Sign Language (BSL) Interpreter. Whilst our service works with BSL interpreters as part of our multi-disciplinary teams, we recognise that being ‘sensitive to their communication needs’ requires a deeper level of

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1. Deaf families; a family when one or more of the members are deaf.
understanding, and we are doing this through communication profiling with the newly developed role of SDOWs.

Communication profiling facilitates the first steps towards achieving a greater understanding of:

- The young person’s language and communication skills and needs
- The communication context of the young person’s family
- The communication context of the young person’s educational placement

The clinical data derived from the communication profile is placed in the wider context of assessment of language need and summarised below.

**Language and communication profiles**

When examining communication between an individual with a learning disability and their support, there is often a mismatch between the language ability and expressive communication between both parties. It is therefore understandable that this mismatch may have adverse effects on the young person. As a specialist service working with deaf children we need to work hard to avoid communication or language mismatch, this not only applies to children with a learning disability but for all children that we work with.

Several tools and resources have been developed to support staff to understand a child’s language and communication needs however these provide details of a child’s skills and needs without noting the context in which they communicate.

Whilst many services gather information about communication and language preferences and needs, there is a lack of literature detailing this work. Hospitals and schools working with deaf children and adults, use profiling tools they have developed locally to adapt the communication context they provide.

Research linked to the Better Communication Project following the Bercow Report identifies the importance of communication profiles for hearing young people with language needs. The results highlighted the importance of profiling individual pupils’ strengths and needs and of using these to personalise learning and education plans, rather than focusing on a diagnostic category of needs to plan intervention. Whilst families using our service will have at least one member who is deaf, their audiological profile or language choice is less important than how their language and communication needs will best be met during any intervention we offer.

Studies have shown that adolescents with language difficulties have the ability to reflect on their own language and communication needs in interviews. These young people show an ability to identify their perceptions of their own strengths and difficulties. They were also able to identify barriers to intervention. Working with a young person to explore what they need to work on and how, will impact on their engagement with the process. Some young people may be less able to do this and need clinicians and family to advocate on their behalf.

Further literature reviews showed that emotional and behavioural difficulties often co-occur with language difficulties in the hearing population, with papers citing 40-90% co-occurrence rates. However within their study they identified that some specific aspects (pragmatic skills, word decoding and low maternal education levels) were more linked to emotional and behavioural difficulties than generalised language difficulties. More detailed information about different aspects of language and communication is needed. This will support our work with an individual and within family or other systems where that deaf person communicates.

Parents face many challenges in understanding the communication and language options available for their deaf child and understanding their child’s needs. This is
often compounded by issues with information exchanged between professionals and parents who do not share a vocabulary for describing; the issues, a model of causality or prognosis, or a shared understanding of what the issues might be, highlight the need for families to receive information and guidance that enhances their participation and fosters their child’s development through information sharing and informed choice. Communication Profiling that involves the family can provide a proactive way of providing this.

Information about language preferences and choices are available from several countries for adult populations. Adults who are sign language users are able to identify themselves as such. Children and young people gradually develop their deaf awareness and identity and current research is investigating how language and identity interlink for teenagers. Communication profiles are widely used to gather information about clients with other disabilities such as learning disabilities. It is a means to identify deficits in communication abilities, interests and social relationships. Interestingly, a project completed in Brazil included a creative protocol to evaluate communication abilities of pre-school children and efficacy of communication including areas such as; turn-taking, getting attention etc.

**Developing Communication Profiles**

Since 2009, National Deaf CAMHS staff have worked to understand how best to be ‘sensitive’ to our clients’ communication/language needs. Over the last two years representatives from across the national service have worked together to develop the Communication Profile and its accompanying with the co-working preposition that deaf and hearing perspectives and qualified BSL/English Interpreters work together.

Staff members who are involved in gathering Communication Profile information have information about language and communication development, alongside the difficulties that can be associated with developing these skills.

The Working Group consisted of managers, interpreters and clinicians (both deaf and hearing). The aims of the project were:

- To improve access for Deaf children and families upon first contact with the service.
- To limit disengagement from children, young people and families
- To develop the following communication profiles:
  1. Child communication profile
  2. Family communication profile
  3. School observation
- To trial Communication Profiles, led by Deaf staff, receive their feedback and amend the Profiles accordingly.
- Provide accessible Communication Profile training.
- Evaluate the Communication Profiles.
- Set standards for the Communication Profiles

The project has been completed in three phases:

*Initial Information Gathering Phase*

The Working Group and other members of staff provided information about language and communication assessment as well as profiling they used within their clinical work. From this we organised initial information sharing days.

*Communication Profile Development Phase*

Following the initial training day, Deaf staff were invited to attend the following training sessions: general language development and development in BSL, language difficulties including specific language impairment, working with qualified BSL/English interpreters and hearing clinicians, report writing and reflective practice. Alongside these training sessions, discussion groups and workshops encouraged all staff to contribute to the development of the Communication Profile and its
guidelines. The training was delivered in BSL, with interpreters working as required. Each training session was recorded onto DVD and copies distributed to each team to ensure participants could revisit and reflect on their learning in their first or preferred language (BSL). Feedback from sessions reported that the training was useful, inclusive and accessible.

The Communication Profile is usually carried out by deaf and hearing staff working together to provide the deaf and mental health aspects. There are three parts to this; a 1:1 session with the child, a visit to the family home and a school observation. Over time we have collected different activities and resources that are suitable for use across the different age ranges. These can be used to structure a session, as a way of engaging the child, adolescent and family, and consequently allow us to gain an insight into communication.

An overview of the information gained from the Communication Profiles is given in the table 1.

The visits are summarised in a report outlining observations and providing recommendations for the clinical team in readiness for the next step in the child and families’ journey through the care pathway. Recommendations focus not only upon language/communication preference but also additional factors:

- Preferred mode of communication/language for appointments; BSL, SSE, Sign and Speech, Speech or Makaton.
- Additional considerations including use visual resources, adapted pre-educative work for new concepts to be explored, adapted emotional literacy work needed or use of support materials e.g. symbols.
- Language service professional required e.g. qualified BSL/English interpreter / Deaf interpreter or lip speaker.
- Identifies involvement of other professionals e.g. a language therapist working with a specific language disorder.
- Raises queries that require further assessment or intervention e.g. Assessment of British Sign Language Development

‘Understanding a Deaf child’ training for the school, family or others, ‘Understanding hearing people’ training for deaf parents with hearing children, level of sight loss or use of amplification.

- The need for a bespoke parenting skills package.
- The need for BSL tuition for the family.
- Request a professionals meeting to share information or a Common Assessment Framework (CAF) meeting.

Evaluation of the Communication Profile showed that it provided key workers with much more information about communication, language and access, culminating in a greater overall picture that enables clinicians to plan their work and give further thought to interventions and their development.

Findings of the Communication Profile also impacted on the practice of others who are involved in the care of the deaf child for example, social care services booked BSL/English Interpreters for appointments and did not rely upon parent to ‘interpret’ or ‘broker’ information. The report and recommendations feed into assessments and remain a part of the care pathway. Updates are needed as a child grows their needs change; ensuring that we are responsive to their individual needs and preferences as they develop.

It is important to note that the depth of a Communication Profile, will vary on a case by case basis. The language features identified, such as the use or comprehension of concrete or abstract concepts, will be noted as they arise. Not all children, young people and families will struggle with abstract concepts such as emotions, however for those children who do, the clinical staff can prepare
materials that will help these concepts become more concrete or relevant to their understanding, for example through the use of pictures or pre-session education (for example, boundaries and consequences).

Communication Profile Dissemination Phase

During the first two phases, Deaf staff members (from both in patient and outreach teams) and the Language and Communication Working Group members worked with their respective teams to utilise and refine the guidelines.

In the third phase of the project, a National Away Day presented information about the project across the wider service. This included different clinicians’ experience of using the Communication Profile reports, the impact this had on clinical interventions and outcomes.

Evaluation of the Communication Profiles

A survey was undertaken to get feedback about team members’ experience of the Communication Profile, outlining both the advantages and disadvantages. All clinical staff that completed the questionnaire noted that the Communication Profile had some benefits; their comments are summarised into the following categories:

- It helps to improve communication and access
- Improves interventions
- Helps with planning work
- Gives a better general picture of a child and family
- Deaf and hearing staff work together
- It helps assessment
- It ensures that we begin by looking at communication

The disadvantages were constructive and insightful, helping us to review the Communication Profile, plan the training sessions and improve their use:

- Delays appointments
- Training needs for all staff
- Understanding the Communication Profile – child, family and staff

The Future of the Communication Profile

Interim plans

The Language and Communication Working Group are aware that the Communication Profile needs on-going development. Following the roll out of the standards in the spring of 2014 and a national audit in the summer of 2014, there was a re-audit in 2015. The aims are to ensure quality of care and best practice in relation to Communication Profiles and to provide opportunity for reviewing and improving practice.

We are currently compiling paper and BSL DVD resources to support the use of the Communication Profile, not only for current staff but making it an integral part of induction for new staff. The resources will be available for staff to access on-line enabling sharing of learning resources and good practice across the national service. We hope to ensure that these initiatives will maintain the co-operative, shared working practice we have undertaken to date. By sharing skills, we are supporting each other in direct communication and improving accessibility for individual’s training and language/communication needs. We are not only becoming more sensitive to our clients’ communication needs but those of their families and carers as well as staff (individual and team) needs.

Long term plans

We need to understand the impact of communication profiling in terms of improved outcomes for families. In addition, the Northern Arm is hoping to develop a consultation project with families and will be looking at how best to involve children and families in the design and development of service initiatives, where we will
discuss the Communication Profile and the impact it directly has on children.

From Communication Profile feedback, Language Brokering\textsuperscript{28} and Deaf Identity have been identified as areas that are lacking both in literature and evidence based data. A small scale study to explore these using the Deaf Acculturation Scale (DAS)\textsuperscript{29} has provided initial evidence of the need to develop tools in these areas.

The integral role for deaf practitioners within our service has been shaped by the use of Communication profiles somewhat, and it is hoped that deaf practitioners will aspire to take these screening skills further and aspire to become qualified language therapists, as appropriate training is developed and the range of clinical assessment tools for this group of children is developed.

Conclusion

As a service we have recognised that a good understanding of a child and their family’s communication, language and access needs leads to in-depth assessment and bespoke interventions. The gradual development and adoption of the Communication Profile has been and will continue to be an iterative process. The ability to audit its use throughout the service will inform this process and consequently we will see the evolution of further assessments, tools and training for use in this specialised area.

References


13. Bercow J. The Bercow Report: A review of services for children and young people (0-19) with speech,


Table 1. Overview of the information gained from the Communication Profiles

<table>
<thead>
<tr>
<th>1:1 with the deaf child</th>
<th>Family</th>
<th>School observation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mode of communication of the child across different settings</strong></td>
<td><strong>Mode of communication/language of the child in this setting</strong></td>
<td><strong>Educational philosophy eg bilingual education or total communication</strong></td>
</tr>
<tr>
<td>Children’s preferred communication/language choice</td>
<td>Environmental factors e.g. seating, lighting</td>
<td>Support in the classroom &amp; at other times</td>
</tr>
<tr>
<td>Children’s level of language/communication, use of language and understanding including productive and receptive skills, Language features; turn taking, eye contact, deaf etiquette and conversational skills</td>
<td>Inter-familial communication</td>
<td>Access</td>
</tr>
<tr>
<td>Identity &amp; culture</td>
<td>Deaf &amp; hearing awareness</td>
<td>Level of language/communication</td>
</tr>
<tr>
<td>Additional needs e.g. visual difficulties or learning difficulties. Access required e.g. interpreter / deaf interpreter</td>
<td>Parenting a deaf / hearing child skills / needs</td>
<td>Attention to task &amp; concentration</td>
</tr>
<tr>
<td>Unusual use of language e.g. when referencing people and events, mannerisms, or incongruence’s e.g. signing the word sad with a happy or neutral face</td>
<td>Resources eg access equipment (vibrating alarm clock)</td>
<td>Environmental factors</td>
</tr>
<tr>
<td></td>
<td>Language brokering</td>
<td>Deaf &amp; hearing awareness</td>
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<tr>
<td></td>
<td>Family relationships &amp; dynamics</td>
<td>Relationship with peers</td>
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<td></td>
<td>Gaining an overview of other professionals involved with the family.</td>
<td>Social times e.g. playtime / free time</td>
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<td>Statement of educational need</td>
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<td>Technical aids e.g. radio aids</td>
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