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**Communication is the key:
Improving outcomes for people with learning disabilities**

Abstract:

Purpose – This paper introduces the Open Communication Tool (OCT) as introduced in “From ‘What do you do?’ to ‘A Leap of Faith’: Developing more efficient indirect intervention for adults with learning disabilities”.

Design, methodology, approach – Qualitative data from a study identifying barriers to effective intervention was used to create a model of working practice.

Findings – This paper introduces a model of addressing intervention which could be used by the broader multidisciplinary team to increase successful intervention outcomes and pinpoint concerns about care providers who do not enhance communication effectively.

Originality / value - The authors suggest that a more consistent and robust approach to delivering indirect intervention could be used to bridge communication gaps between healthcare providers and commissioners / monitoring bodies of services for people with learning disabilities.

Keywords: *Learning disabilities, indirect intervention, multidisciplinary working, commissioning, outcomes*

Paper type: Research paper.

Easy Read Summary

People who work for the NHS go into the homes of people with learning disabilities. They suggest ways that staff can improve the lives of people with learning disabilities.

Sometimes these things do not happen, or they happen for a short time and then stop. An earlier paper looked at the reasons that this happens.

This paper uses the information from research to suggest a way that health professionals can work best with people who run residential and day-services.

This paper suggests that this way of working can be useful to find out which services are not working well, and tell commissioners and social services about these homes and day centres. One suggestion is using the Open Communication Tool (OCT) to identify where areas of need are.

This paper hopes that telling people about problems with working together early on will help to stop bad things happening to people with learning disabilities in these places.

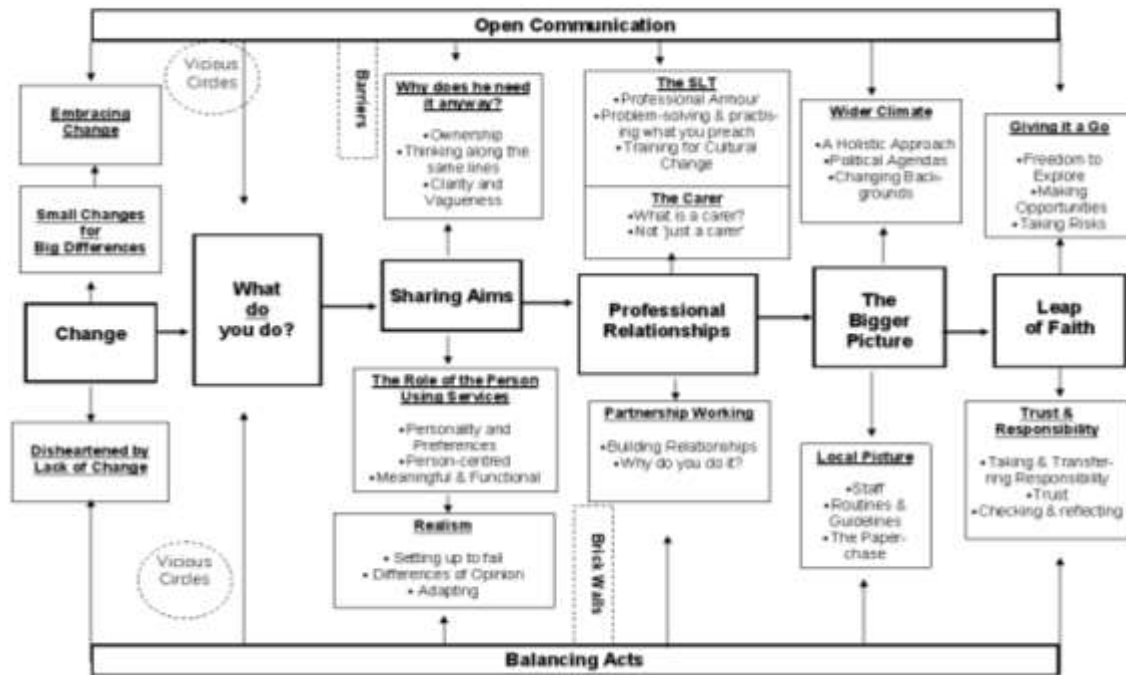
Background

The research underpinning this paper started as an attempt to improve understanding of barriers to achieving successful communication outcomes for people with learning disabilities as undertaken by speech and language therapists (SLTs) (Lewer & Harding 2013). As it progressed, it became apparent that the difficulties noted by SLTs in achieving successful communication reflect much wider challenges in the provision of good quality services for people with learning disabilities.

Many reports and government documents have highlighted inequalities and abuse within services for vulnerable adults and offer general information about how the situations should be improved (McGill, 2011). However, too often it appears that nothing is really changing (Mencap, 2012) and there is a need for more concrete procedures to be trialled and evaluated on a regular basis. A major issue that keeps emerging is that people with learning disabilities are not consulted about what their needs actually are, and if they are asked, the communication supports and strategies needed to achieve effective communication are not readily available, or if they are available, they are not utilised (Mencap, 2012).

A series of themes, relating to values, attitudes and role-perceptions were identified by grounded theory analysis (Glaser & Strauss, 1967), of data gathered from support-workers and SLTs; these were mapped onto the process of delivering indirect intervention and indicate where barriers to successful outcomes can occur (Figure 1).

Figure 1: The process of planning and delivering indirect communication intervention

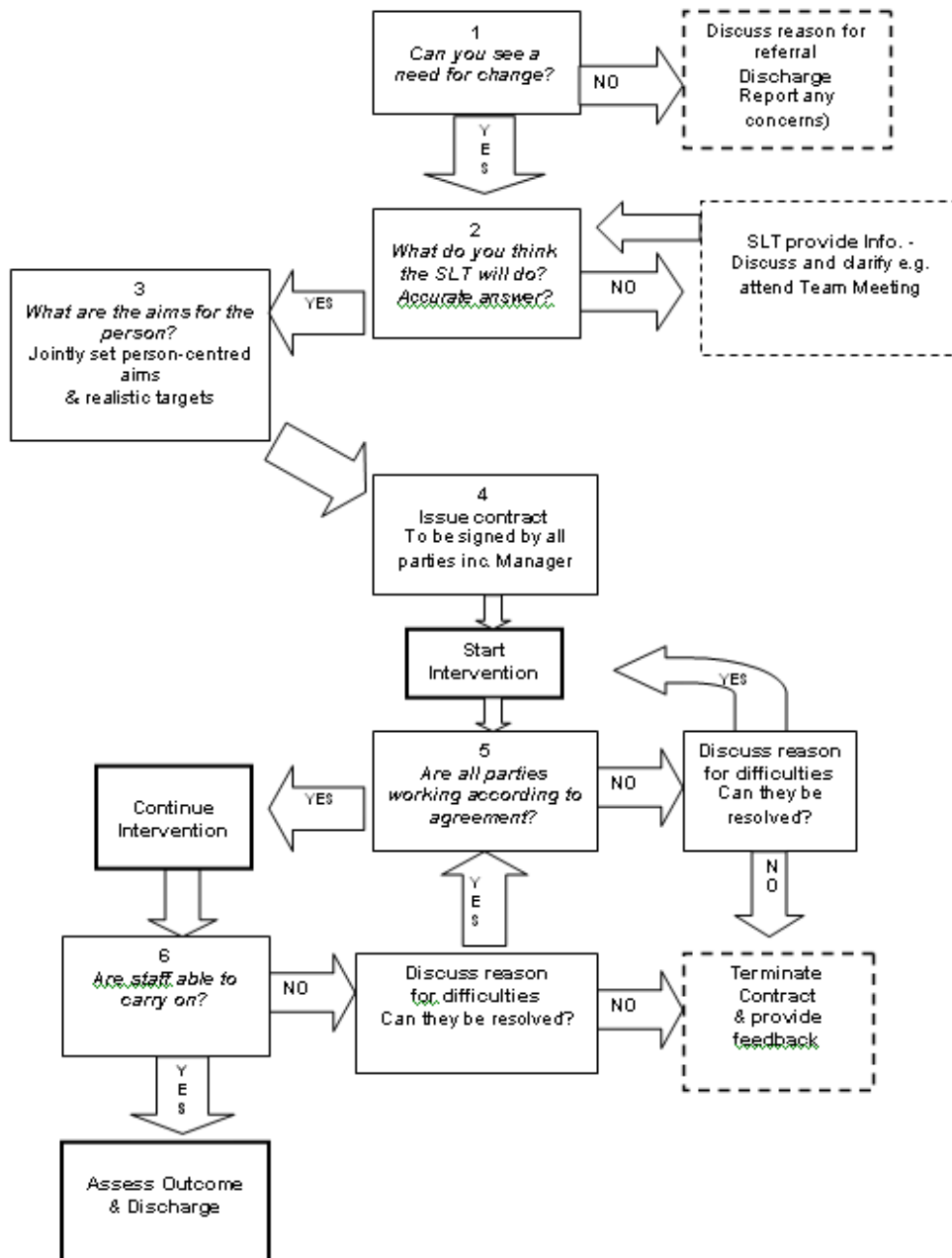


Using the themes identified in this study, a tool (The Open Communication Tool, Figure 2) has been developed which professionals can use in indirect intervention to ensure that each of the potential barriers have been identified and attempts made to overcome them. As there is no guarantee that professionals all perceive skills and difficulties in the same way (Koski & Launonen 2012), a standardised process of addressing indirect intervention such as The Open Communication Tool could be helpful.

The Open Communication Tool (OCT)

The following flow chart (Fig. 2) uses the evidence gathered from the study to inform a process by which intervention can be undertaken. Each stage correlates with themes uncovered in the study and is measured by questions or evidence to discover whether a barrier exists at every step of the intervention process.

Fig 2: Using purposeful questioning to facilitate indirect intervention: The Open Communication Tool



Question 1: Change

Can you see a need for change – what change needs to take place?

This question should be asked to the service-user, key-worker and organisational manager. If the level of direct questioning is not appropriate for the service-user, the therapist can gather information through case history (and often previous SLT / MDT guidance). Involving

the Manager from the outset is crucial as they have a role in ensuring every step of the intervention process is effective, and also have some ownership in the whole process.

Sometimes referrals are inappropriate, unrealistic or made without full understanding of the SLT's role in supporting the service-user. If, at this point, all parties involved cannot agree there is a need for change, then intervention may not be necessary. If the SLT can see a need for change in the communication environment, but this is not acknowledged by the organisation, intervention is unlikely to be successful as devising a shared aim will be impossible.

Question 2: 'What do you do?'

What do you think the SLT will do? What do you expect to do?

If the need for change has been established, then the role of the SLT needs to be addressed and clarified to ensure all parties have realistic expectations of the intervention process. If it becomes apparent that there is no clear understanding of the role of the SLT, then it is the SLT's responsibility to address and clarify the issue before intervention can proceed. Some of these expectations can be addressed through frequent and short bursts of training so that support staff can understand the facilitative nature of SLT intervention and its ethos of maximising a person's communication competence in relation to achievable goals. Ensuring accessibility and on-line problem solving with the SLT to question and check implementation of the strategy is also necessary to enable more accurate understanding of the expected intervention.

Question 3: Sharing Aims

What is the aim for the person using the service?

At this point, person-centred aims can be set which must be agreed upon and owned by all parties. As in all therapeutic goal setting, the person using the service is central to this process and goals need to be meaningful, functional and evidence-based. The more functional the goals are, the more likely they will be integrated and used on a daily basis. The environment can also mean involving other service users who may live with the person receiving the intervention. Involving other service users can have powerful benefits for all involved (Harding, 2008). In addition, in indirect intervention where the aim is to effect change

in the communication environment, the aims need to additionally be realistic for the service delivering intervention. This aspect may not always be fully appreciated by SLTs or other MDT members when setting intervention goals and a lack of realism at this stage only sets a service up to fail.

Stage 4: Clarify professional roles in writing

This is how we will achieve this aim

Aside from writing the agreed therapy goals, a written contract, agreed by all parties is useful in clarifying roles and responsibilities and highlighting points of potential breakdown in intervention and what to do if problems are identified. It ensures SLTs, managers and support staff are aware of their responsibilities, including attending training or appointments.

Question 5: The Bigger Picture

Are all parties working towards the service-user's aims as agreed?

By following steps 1 – 4 of this process, the SLT takes responsibility for maximising the opportunity for successful intervention. Some things are beyond the control of the SLT however; if staff do not attend appointments or do not carry out agreed actions, discussion is needed to identify the reason for breakdown. Part of this discussion could involve if the goals and strategies identified are manageable, and what the actual problems in delivering intervention are. If the first stages have been fully addressed, this should reduce the likelihood of these areas being the reason for break-down. Often, the issues exist at a wider level – e.g. problems with consistent staffing, organisational changes or different values and priorities. The SLT also needs to be able to reflect on whether the shared aims were genuinely established at the outset and whether there is anything they have themselves omitted or could have facilitated in a different way. Addressing this issue is complex and merits further discussion below.

Question 6: Leap of Faith

Are the staff able to carry on?

If all parties have attended meetings / training sessions and are working towards achieving the goal for the service-user, there is a point at which the SLT needs to have faith in the staff

team to carry out intervention independently. It is important to reflect on experiences and check that staff feel they have the confidence to continue before discharging.

'...the only thing I would say is if, in the back of my head, I knew that (the SLT was going to pop in once every 3 months, it wouldn't have lapsed.' (C2)

There is a valid argument for running 'top-up' intervention or training which would help to maintain skills and skill-up new staff (Chadwick & Joliffe 2008, Chatterton 1999). Certainly, the maintenance of regular contact, both in person and via other networks can help maintain and sustain the intervention plan and also support the notion that therapy strategies are often about maintaining and maximising communicative competence rather than achieving dramatic changes (Chadwick & Joliffe 2008, Chatterton 1999). This would help to build professional relationships and maintain awareness of the SLT role, reducing the amount of time needed for indirect intervention.

Discussion

Introducing the tool

The following case study describes the use of the tool in a multidisciplinary context. The bracketed numbers refer to the questioning stages of the tool.

Fig 3: Case Study: implementation

The following case study describes the use of the tool in a multidisciplinary context. The bracketed numbers refer to the questioning stated in the body of this text.

Background:

X had been referred to speech and language therapy. She is a non-verbal communicator with some needs-based intentional communication who lives in residential accommodation with 24 hour support. Initial SLT screening assessment had identified the need for intensive interaction to develop relationships between X and staff and objects of reference to be used to support X's understanding. X had also received intervention from Behavioural Support Services and Occupational Therapy.

Staff and Managers had attended training and received intensive input from all disciplines, but little or no carry-over was observed. The training and ideas were not new to the service; they had received considerable input from the MDT over the past ten years but they still did not seem able to implement recommendations. Opportunities for interaction were few and staff morale was low.

All professionals had noted the lack of engagement in the home which meant that service-users were often seated alone in the lounge, with the TV and radio on and no staff members present. These concerns had been recorded and discussed amongst professionals but there was no clear quality alert process in place and the issues did not meet the Social services criteria for safeguarding.

All 4 residents in the house were then referred to SLT, OT and BSS by Commissioning following safeguarding alerts relating to physical abuse of X which was observed by a member of the public.

Process:

Discussions were had with the **Home and Service Managers** who agreed there was a need for **change** (1). The **professional roles** were explained and the fact that staff would need to do a great deal of the work and monitor progress was clarified. (2)

In **joint goal setting** discussions (3), it became apparent that staff did not necessarily attach value to communication or engagement and were not aware of or did not feel confident in implementing strategies.

The **shared** aim (4) was: to increase communication, engagement and activity opportunities for the service-users.

In-house training was delivered which was **attended by permanent staff and the Manager**. (5) Despite signing a contract agreeing to attend the training, the service manger did not attend. Much of the training centred on **open discussions**, problem solving around how staff could achieve the aims, and breaking the aim down into manageable steps which could be monitored (e.g. recording time spent with service-users, recording responses)

Monitoring forms were designed with staff to fit in with **existing paperwork protocols**.

For 3 months, **staff took responsibility** (6) for implementing and monitoring recommendations. MDT input consisted of regular phone calls to the Manager and 2 follow-up visits.

At a final training session, monitoring forms were reviewed and service-user **interaction opportunities were found to have increased significantly**. **X was recorded as having expanded her repertoire of communication skills, reducing behaviours which challenge and increased participation in activities** was also noted. Similar gains were made by the other service-users.

Safeguarding issues have been resolved and closed.

The next step of the progress will be to ascertain whether staff continue to use good practice to support the people in their care. If carry-over is not observed and levels of care deteriorate - the fact that the Service Manager did not fulfil his commitment to attend training will be addressed and highlighted as a potential barrier to quality care provision to the commissioning and social services teams.

A standardised outcome measure for the tool has not yet been established and requires further consideration. As it is designed for multiple purposes the outcome measure is likely to be multi-factorial and will need to address the following:

- *Achieving goals of intervention* ; (these would be measured in the usual way using a standard outcome measure such as Therapy Outcome Measures (Enderby & John 1997). The aims will be clearly set out in the contract at the outset and the method of recording change (e.g. monitoring sheets, videoing or other tools) would need to be agreed with the addition of gaining consent for video recording.
- *Sustaining a successful outcome*; it would be essential to build in a review period for the process of intervention. The length and feasibility of this review period is likely to depend on the protocols of individual teams.
- *Aiding reflection on practice*; in a large scale, multi-disciplinary trial of the tool, this could be achieved via questionnaire feedback as well as building into support and supervision sessions so that the cultural notion of embedding reflection about intervention becomes a core value of a team, as well as enabling opportunities to speak freely about communication strategies and supports.
- *Reducing re-referrals to the service*; a pre- and post- audit of referrals over a stipulated period would help to ascertain this.
- *Improving reporting of 'low-level' concerns*; this could be audited through clinical notes and reporting of concerns to management.
- *Alerting Social Services, Commissioning and CQC to concerns about quality of care more quickly*; this would be difficult to measure, but an audit of clinical notes would indicate whether more timely responses to concerns are recorded.
- *Reducing safeguarding concerns*; this would involve identification of risk assessment reporting.
- *Improving quality of care for the service-users*; a wide range of measures should be considered including gathering service-user , advocacy and carer feedback.

What to do if breakdown occurs

According to the original study (Lewer & Harding 2013), SLTs have frequently continued to modify intervention aims in order to achieve a level of success, have kept cases open in the hope of a change occurring, or have discharged in the expectation of receiving a repeat referral for the same communication issues. The same is anecdotally true of other health professionals in learning disability services, as indicated by re-referral rates and longstanding open referrals. This situation is increasingly hard to justify in light of continuing service and economic list pressures.

If the professional has taken responsibility for minimising break-down and break-down still occurs, what should they do?

Learning Disability Team members often feel that withdrawing intervention from service-users in services which do not meet identified needs is unethical. While there are clearly serious ethical considerations in withdrawing treatment (Mencap 2012), there are also ethical considerations, notably collusion, in continuing to work with poor services. By continuing to commit resources, waiting lists grow longer and time for intervention which could be successful is reduced. Colluding with services which do not provide adequate support for people with learning disabilities does not benefit the population as a whole, nor does it benefit the individual service-user who continues to live in a sub-standard situation. It is important that we recognise the distinction between withdrawing treatment in a medical context and withdrawing intervention from an organisation which is struggling to prioritise its service-users' needs.

The case study in which this tool was trialled is not an isolated example. Services in which multiple safeguarding concerns are raised are often those in which indirect intervention has been unsuccessful. In 'Early Indicators of Concern in Residential Support Services for People with Learning Disabilities (Marsland et al 2012), six main areas of concern are highlighted. The themes were gathered from MDT reflection about services where abuse was subsequently found to have taken place. These are closely linked to the barriers to achieving outcomes identified in this project, and include:

- Concerns about management and leadership
- Concerns about staff skills, knowledge and practice
- Concerns about the service resisting the involvement of external people

The document is clear that the risk of poor care is linked to a spread of indicators. Using the 'Early Indicators' document in conjunction with a consistent intervention process such as the Open Communication Tool (OCT) may help to prevent abuse taking place.

Leadership

The case study in this paper signposts the importance of leadership in organisations which provide care; the research underpinning this too highlighted the importance of managers in the successful intervention process. Quality of management and leadership is hugely

variable but vitally important in these areas and increased training and a wider recognition of core competencies is needed (Clement & Bigby 2012, Curtis et al 2011). If health professionals do not highlight concerns about lack of leadership, the situation is unlikely to change. This is not about demonising individual staff but recognising the high level of skill needed to change a culture of poor practice (McGill 2011).

Strengthening Links between Services

Links between learning disability health teams, social services and commissioners vary considerably but there is a strong argument for developing more robust reporting channels and accountability so that if intervention is withdrawn due to a service's inability to carry out their role in indirect intervention, this information is immediately fed back to social services and to the commissioners who pay for that service. The monitoring body, CQC, themselves highlighted the improvement in their assessment process brought about by including professional advisers (CQC June 2012). Inspections often appear to focus on paperwork rather than people and risk being primarily a tick box exercise. By liaising more consistently with health and social care professionals who have longstanding relationships with providers, assessors could arguably gain greater insight into the care provided. In the past, questionnaires were circulated to health professionals prior to inspection but this practice now appears variable.

McGill (2011) comments that 'closed' services are those who foster poor practice; a culture of transparency between care providers and other agencies could help to reduce the risk that people with learning disabilities suffer harm at the hands of those paid to care for them. He also highlights the risk that Winterbourne will be viewed as an exceptional case rather than a sobering indication of hidden issues throughout learning disability services. It is easy to point fingers but if we do not take this opportunity to scrutinize our own practice within the broader context, we are not learning the lessons that have been highlighted for us.

Summary of Potential Benefits:

There are multiple potential benefits of using an evidence-based tool to inform and audit indirect intervention processes as part of a wider reporting system

For people using our services:

- More successful intervention aims reached
- Earlier reporting of poor standards of care
- Prevention of abuse

- Ultimately, fewer sub-standard homes
- Improved Quality of Life

For MDT:

- More successful outcomes
- More robust practice
- Development of more robust values
- Reduction in re-referral due to lack of intervention carry-over
- Increase in effective working
- More effective use of resources
- Demonstration of value for money
- Improved joint working practice

For Social Services / Commissioning / CQC:

- Closer links with MDTs who often know services well
- Increased information-gathering potential
- More prompt response times
- Avoidance of safeguarding procedures (when issues are raised at quality alert level)
- Improved standards of services

Conclusion

In this period of instability, change and financial constraint for people with learning disabilities, learning disability teams have a significant role to play in ensuring the needs of their service-users are met; confirming that our own systems are as robust as possible when carrying out indirect intervention is one step in the right direction. Improving communication and transparency between care providers, health and social care professionals, commissioning and monitoring bodies has been frequently highlighted as essential in reducing the risk of abuse, but few concrete steps have been taken to achieve the goal; this model of working is one method we could trial to put this into practice.

When intervention breaks down, rather than accepting that these are 'poor services' but continuing to work in the same way, perhaps professionals need to accept that not all change is within their control and work within a wider multi-disciplinary context, ensuring information is passed on to the correct monitoring bodies. By basing practice on an evidence-based pathway and using the most robust tools at our disposal to identify where

breakdown has occurred, the MDT can inform often stretched contracts monitoring services and identify problems before a serious safeguarding situation is reached.

In the wake of funding cuts and the cessation of many advocacy services, it is more crucial than ever that members of the multi-disciplinary team work consistently together to ensure the voices and concerns of people with learning disabilities are heard.

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