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Feature

From “what do you do?” to “a leap of faith”: developing more effective indirect intervention for adults with learning disabilities

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Abstract

Purpose – The purpose of this paper is to analyse some of the factors which affect the implementation and outcomes of indirect intervention for people with learning disabilities in residential homes and day centres.

Design/methodology/approach – Data were gathered through a series of semi-structured interviews which were transcribed and analysed according to the principles of grounded theory. In total, four carers/support workers and three speech and language therapists (SLTs) were interviewed.

Findings – Analysis of the data indicated distinct areas where intervention breakdown could occur, some of which were within the SLTs’ control and some of which were not.

Originality/value – This paper builds on previous research to identify barriers to successful therapy outcomes and develops a way of looking at these barriers which can inform intervention planning and delivery.

Keywords Learning disabilities, Adults, Residential homes, Social care, Therapists, Speech and language therapy, Indirect intervention, Multidisciplinary working, Outcomes
Paper type Research paper

Background

Many people with learning disabilities are likely to require some form of support for receptive and/or expressive communication disabilities (Gillberg and Soderstrom, 2003). The tiered model of health and social care (Baker et al., 2010; Figure 1) identifies that speech and language therapy intervention for this client group can be delivered at any level from promoting community involvement to specialist one-to-one intervention, but most speech and language therapist (SLT) work requires working within tier three – developing “capability in specialist learning disability services”. Generalising new skills to different environments and contexts is challenging for people with learning disabilities so direct (tier 4) intervention alone may have limited effect (Money, 1997). Consequently, following assessment, SLT intervention focuses on developing the skills of those who care for and support people with learning disabilities (Parrott et al., 2008).

A key challenge of delivering and evaluating indirect intervention is the therapist’s reliance on the service user’s support staff to carry out recommendations. The skills and attitudes of staff can be highly variable, as highlighted in recent scandals such as Winterbourne View

(McGill, 2011).

Despite the proportion of SLT intervention for adults with learning disabilities delivered through indirect therapy, there is limited research into what influences successful outcomes. Graves (2007) identified four “broad factors with the potential to influence indirect therapy”, one of which was “guiding values and attitudes”. Exploration of this theme and “perceptions of role” formed the basis of this study. The interplay of role perception, values and attitudes is complex and its effect on therapeutic outcomes is not fully understood. This paper seeks to further understanding of these issues and to suggest a framework for a robust, indirect therapy model which maximises the likelihood of a successful outcome.

Values

Societal values and cultural beliefs have always impacted significantly on the lives of individuals with learning disabilities and the support they receive (Bridges, 2004; Colodny, 2008; Mansell et al., 2008) and can be a challenge to implement (Burton and Kagan, 2006). Hickman (2002) lists various sources of values and beliefs including the World Health Organisation, “normalisation” principle (Nirje, 1994), Wolfensberger’s (1983) “Social role valorisation”, valuing people and person-centred planning (Department of Health, 2001, 2006, 2007).

Perceptions of role

Perception of role in this context is complex: the SLT’s and carer’s views of their own and each other’s professional roles can affect indirect therapeutic outcomes (Money, 2002). Both roles are multi-faceted; the role of therapist can encompass educator, advocate, medical professional and counsellor among others (Ukrainetz and Fresquez, 2003). The professional carer’s role is equally open to multiple interpretations depending on whether they view themselves as maternal or enabling, facilitative or protective (Graves, 2007).

Attitudes

“Attitude” is a difficult term to quantify and its influence hard to locate; parental attitudes have been noted to influence effective outcomes in paediatric therapy (Marshall and Goldbart, 2008) and the attitudes of professional support workers are similarly important in intervention for people with learning disabilities (Graves, 2007). “Compliance” with SLT recommendations has been explored in the field of dysphagia (Crawford et al., 2007; Colodny, 2008) but the term seems rarely used in reference to indirect communication therapy. Differing attitudes can render this relationship problematic, affecting the outcome of intervention.

The attitude of carers towards the people they support is fundamental to interaction style and ability to participate in intervention (Mansell et al., 2007). Awareness of these attitudes and beliefs may be limited (Purcell et al., 2000) and carers’ attitudes may conflict with those of the SLT (Graves, 2007). This imposes additional barriers to effective indirect therapy and to maximising the development of the service user’s skills (O’Brien, 1981).

Methodology

A qualitative research method was adopted whereby data was gathered through interviews with practising SLTs and professional support workers within one NHS Trust.

Interviews

Interviews were semi-structured, which allowed questions to be added or omitted in order to explore emerging themes more fully; each interview lasted around one hour and the initial structure (see below) differed slightly for each professional group.

Initial interview plan:

1. Can you tell me about your job? How do you describe it to people who do not know much about this sort of work?
2. What made you want to be a support-worker/SLT?
3. What are you aiming for with your service users?
4. What do you like most about your work?
5. Does your organisation have a written “philosophy of care”?
6. Have you heard of valuing people/valuing people now?
7. Do you often work with other professionals?
- 8a. Have you ever worked with an SLT – was it what you expected? (Support workers)
- 8b. Can you give a brief outline of a piece of successful collaborative working? (SLTs)
- 9a. What did you have to do? (Support workers)
- 9b. Can you outline a piece of unsuccessful collaborative working? (SLTs)
- 10a. How did you feel about what you were asked to do? (Support workers)
- 10b. Could you have done anything differently? (SLTs)
11. What are the most important communication opportunities for your service users?
12. Do you feel the job you do is important?
13. Could you tell me five values which are important in your job?
14. In an ideal world, what would you change about your job?
15. Is there anything else you would like to add?

Recruitment

Participants were recruited from one county, served by Community Teams for People with Learning Disabilities under a single NHS Foundation Trust. All the SLTs from this Trust were invited to take part. This was a time limited project, hence the small sample size.

In recognition of the fact that responses were likely to be shaped by personal background as well as professional environment, attempts were made to recruit participants from a wide demographic; where possible, theoretical sampling was used to select participants of different gender, age and ethnicity from within the two professional groups.

Analysis

After transcription of the interviews, data were analysed through a grounded theory approach (Glaser and Strauss, 1967).

Findings

Central and subsidiary themes emerging from the data analysis were mapped onto the process of planning and delivering indirect communication intervention (Figure 2).

Each of the major themes identified in Figure 2 are now considered in more detail.

Supporting quotations from interviews are coded as C for carer, S for SLT.

Change

Reactions to change were sometimes positive – embracing change as a positive step and seeing significant development from small changes:

... the change and development thing – it’s very satisfying (C4).

you’re focused on a real small benefit which actually could have a huge benefit in their life (S3).

Sometimes, however, interviewees reported finding lack of enduring change disheartening:

As long as it has a long-lasting “oh yes!” – which probably doesn’t happen (S1).

The negatives about it are if you don’t see any results from whatever we’ll be working at (C1).

Attitudes to change are central to the success of intervention and need to be considered during goal setting. Change management is a growing field in many contexts in the NHS and there are a number of models which may contain useful frameworks for therapists working indirectly in this field (Bamford and Daniel, 2005).

The themes related to change are summarised in Table I.

What do you do?

I weren't too sure what it was all about . . . because obviously it was on a client who couldn't speak (C3).

Analysis of the data revealed the importance of clarifying the SLT role in achieving successful intervention, also identified by Graves (2007). The job title "speech and language therapist" is potentially misleading when working with clients who are non-verbal communicators. The term "therapist" instead of "trainer" or "adviser" also is suggestive to many carers of a 1-1 working relationship between "therapist" and "patient" and so they are unprepared for the expectation that changing their own working practice is key to supporting and developing a service user's communication skills (Graves, 2007). A failure to address expectations clearly at the start of the intervention can lead to confusion and resentment.

Sharing aims

Often staff members are not motivated because, just because CSCI or . . . regulations say something is wrong, they just don't see how (S3).

Without joint ownership of therapeutic goals, the likelihood of effective, enduring outcomes is practically nil. Basing goals on service users' needs and preferences was identified as essential but a number of barriers to identifying and achieving shared aims were identified within the study; these ranged from difficulties in seeing a need for change in communication practice on the part of the carer to a failure to set realistic goals on the part of the therapist: . . . so look at what's possible, look at what the staff team can achieve (C2).

The themes related to sharing aims are summarised in Table II.

Professional relationships

And you think to yourself, these are specialised people, so you kind of meet people halfway (C4).

. . . Being able to admire the care they offer, hopefully, by acknowledging that I couldn't in a million years do what they do (S1).

In order to ensure that progress in shared aims is maintained and achieved, building an effective professional relationship based on mutual respect is fundamental. The values of carers and SLTs may not be aligned which means that the SLT must adopt a problem-solving approach and consider therapeutic goals more broadly; training and modelling should be a significant part of intervention (Royal College of Speech and Language Therapists (RCSLT), 2006), ideally involving the service-user as well as the SLT and carer:

The more you work, the more you realise that the manager is really the key to it all being successful (S3).

The role of the manager within a service for adults with learning disabilities is not always formally recognised within research and guidance as distinct from that of the workforce but this study indicated that working with the manager as well as staff had a greater and more enduring effect than working only with a key worker.

The themes related to professional relationships are summarised in Table III.

The bigger picture

There is never an opportunity to stand still . . . (S1).

I'm . . . quite naïve to it all but people who've been here for donkey's – they get a bit . . . apathetic about it (C4).

Continually shifting political, ideological and financial backdrops at national and local levels make working in learning disability services challenging. Vulnerability, powerlessness, frustration, disillusionment and apathy were all reported and cannot help but impact on therapeutic relationships and outcomes. While aims for intervention need to be realistic for the service user, they need to be realistic within the organisational context too. The need for a holistic, multidisciplinary approach is well documented in the field of adults

with learning disabilities (Mencap, 2012; RCSLT, 2009); it is not possible to devise effective intervention for communication without taking into consideration other health and social needs. From this study, it became apparent that a holistic approach needed to go beyond the needs of the individual to the needs of the organisation that was supporting them, if intervention was to have a successful outcome. Frequent staff changes, reliance on agency staff, or a lack of support or guidance from the manager were all identified as potential barriers to achieving successful outcomes.

The themes related to the bigger picture are summarised in Table IV.

Leap of faith

And the staff team . . . just got behind it one hundred per cent . . . whether they thought it was going to work or no, they did it without fail, faithfully (C2).

Even after roles have been clarified, shared aims established, training delivered and professional relationships developed there is still a moment where faith is needed to ensure progress. Without this, there is a risk of the “sabotage of non-compliance” (Colodny, 2008) and an ensuing vicious circle.

This study identified some necessary factors for this next step to take place. First, there need to be opportunities for communication and sadly there are still many services where meaningful engagement is neither valued nor practiced (Bradshaw, 2005).

Attitude towards risk is central; although the risks of impoverished communication environments are well documented (Marshall and Goldbart, 2008; RCSLT, 2009), these may seem less immediate than the risk of “getting it wrong”. Alongside the theme of faith, trust emerged as crucial to the success of indirect intervention; a trust that is essential in all four strands of the professional relationship, service-user, therapist, support-worker and manager. The freedom to explore was reported as crucial; carers need to feel free to give strategies a try without fear of rebuke from others if things do not go smoothly.

The themes related to a leap of faith are summarised in Table V.

Other themes

Additional themes arose from the study which were not identified as stages in a process, but are concepts which permeate indirect intervention. Results indicated that carers and SLTs alike were often struggling to balance the multiple components of their role, which impacted on the ability to carry out intervention. The importance and value of open communication is clear. Results from both carers and SLTs reflected an awareness of barriers and cyclical processes which could not be resolved, such as difficulties accessing services or repeat referrals for service users. Within the theme of barriers, the idea of “disengaging” is key and can occur at any time within the intervention process.

Discussion

The results of the study suggested a number of concepts which have the potential to influence successful communication intervention for people with learning disabilities. Building relationships and affecting attitudinal change are not quick processes and do not fit easily within dictated time constraints, affecting the measurement of outcome success. By explicitly acknowledging how values, attitudes and role perceptions can affect the intervention process, SLTs can create a more robust and timely process for intervention and more in-depth reflective practice.

The researcher’s aim is to create a model of intervention grounded in the evidence obtained from this project as summarised in Figure 2. This would be used to identify and overcome the barriers when delivering indirect intervention and would increase accountability both for SLTs and for the staff and organisations who support people with learning disabilities.

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