Intellectual disabilities: improving access to therapeutic communities

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Access to specialised therapeutic communities (TCs) for people with intellectual disabilities (IDs) such as ‘Camphill communities’ and ‘TCs plus’ is limited and patchy in the UK. Nonetheless, the emphasis for some time now has been to enable people with IDs to access mainstream services, which have a legal duty to make reasonable adjustments to facilitate this. Here, the authors propose a set of recommendations in order to improve the access of people with ID to mainstream therapeutic communities and enhance the services they receive.

Intellectual disability is recognised by IQ less than 70 and significant difficulties in coping and social skills in addition to cognitive disabilities started at the developmental stage.

Epidemiologically, IQ forms the basis of comparison between studies, and IQ <50 is generally used to define ‘severe’ intellectual impairment, with prevalence between 0.16 and 0.73% in contrast to ‘mild’ intellectual impairment group with IQ between 50 and 69 (prevalence of 2.27%).

The experience of stress negatively impacts the psychological well-being of adults with ID. Adults with mild ID report experiencing more frequent and severe stress from negative social interactions compared with other categories of stressful events and have greater difficulty coping with stressful social interactions than other categories of stressful events.5–7

Psychotropic medication is widely used in individuals with disabilities: between 30% and 40% of individuals receive psychotropic medication. Polypharmacy rates vary between 5% and 10%. In hospital settings use of antipsychotic medication varies between 22% and 45%, and in the community it is used in about 20% of cases.8

One study in the UK has suggested that up to 40% of people with mild-to-moderate learning difficulties fulfil the criteria for severe personality disorder.9

A significant number of people with ID have limited cognitive resources to cope with life experiences that often include isolation, facing abusive or neglectful circumstances during their formative years. These individuals are more likely to use ‘problem-focused’ coping strategies that develop earlier than ‘emotion-focused’ coping, which requires complex language and metacognitive capabilities to alter negative affect.10,11 Problem-focused coping involves attempts to alter the stressful situation itself, while emotion-focused coping involves efforts to alter negative affect surrounding a stressful situation.12,13

This is likely to lead to unmet needs in their primary emotional experiences and therefore they are likely to benefit from joining the TC.

Psychological interventions such as ‘dialectical behavioural therapy’ (DBT) and TCs are considered as treatments of choice for personality difficulties.14,15 The main aim of group therapies is the formation of healthy personality by providing the necessary primary emotional development experiences, by addressing issues of attachment, containment, communication, inclusion and agency. These can be deliberately recreated in therapeutic environments to form a structure for ‘secondary emotional development’.

TCs are ‘psychologically informed planned environments’ where the social relationships, structure of the day and different activities are all designed to help individuals’ health and well-being through the core principles of democratisation, permissiveness, reality confrontation and communalism. TCs are typically structured so that the ‘working day’ is divided between formal psychotherapeutic
activity (small group therapy and community meetings) and educational/occupational activity (eg skills training, occupational therapy sessions). The remainder of the TC day, including meal and leisure time, is intended to provide positive, pro-social experiences. Community members are encouraged to be involved in planning community activities.17

A modified therapeutic community programme has been proposed in order to help this vulnerable and deprived population.18 There are few papers in favour of specialised TC for people with ID.19,20 Currently in the UK there are two specialised organisations using TC models for people with ID. One of them is called ‘Camphill communities’ and the other ‘TC plus’.19,20 The main critiques are the lack of level I and II evidence, highly specialised pathway, limited in number and difficult to access for most patients with ID.

Camphill group communities were developed in the 1940s and were originally known as intentional communities. Members of the community live and work together as active participants in each other’s lives. Community members and staff members share the work required for communal living, with staff taking on a facilitator/mentor role, rather than a traditional staff/resident role division. A strong value set underpins the principles of Camphill communities, which promotes a spiritual model, while providing a sense of belonging for people who are often marginalised within wider society. The group consists of only 23 communities in England and Wales and includes independent residential and day schools, specialist colleges of further education and adult communities where each individual’s abilities and qualities are recognised and nurtured as the foundation for a fulfilling life (more information at: www.camphill.org.uk). Other specialised TGs are established in prisons for offenders with ID.

TC plus is a pilot study launched by HMP Dovegate. Rampton hospital has launched a similar service in recent years as well.19,20 Outcome evidence from an evaluation of the treatment model developed in the National High Secure Learning Disability Service at Rampton Hospital20 suggested that at 12 months rates of seclusion were found to have dropped by 70% for men (all with mild ID) who resided in a TC, while a comparison group receiving treatment as usual (TAU – including offending behaviour programmes and DBT) demonstrated an increase in seclusion rates over the same time period. Staff rating scales measuring internalising problems such as anxiety and somatising also indicated significant improvement in the TC group over time, and particularly in relation to the TAU group.

Despite much evidence in favour of using group therapy, family therapy and supportive psychotherapy in people with IDs,21–23 there has been no publication focusing on the use of generic therapeutic communities in people with ID and personality disorders. In addition, it is accepted that low IQ would decrease the opportunity for adequate treatment and warrants some adjustments to the services.24

The aim of this project is to propose a set of recommendations in order to improve the access of people with ID to mainstream therapeutic communities and enhance the services they receive.

**Method**

To achieve the aim of the study, we used the ‘seven-step improvement process’ model introduced by Information Technology Infrastructure Library (ITIL) as our conceptual framework. The model is conceptualised in Figure 1.

Stages 1–3 of the seven-step improvement process are compatible with methods in academic writing. Stages 4 and 5 could be considered as findings and conclusions. Disseminating the recommendations through publishing the paper in an esteemed journal and implementation of them by mental health professionals will close the loop by providing stages 6 and 7.
**Identify the strategy for improvement**

We chose the strategy defined by the Department of Health in 2001.23 Emphasis now is to enable people with ID to access all generic services, who have a legal duty to make reasonable adjustments to facilitate this.

In addition, the emphasis for some time now has been to enable people with ID to access all mainstream services, which have a legal requirement under the Equality Act 2010 to make reasonable adjustments to facilitate this. Similarly, recent guidance for commissioners of mental health services for people with ID suggests that services be provided alongside mainstream mental health services so that the skills and expertise from both can be employed to respond to individual need.26

**Define what you will measure**

Given the practical approach of this service improvement project, we focused on the following aspects:

- reviewing the possibility of using generic TC for people with ID
- identifying the pros and cons
- and finally, recommending required adjustments.

**Gather the data**

To achieve the objectives outlined above we needed the application of qualitative methods in their most fundamental sense in order to gain valid insights, develop theory and aid effective decision making. We chose two methods that have seen a steady growth in their application both in academic circles and in marketing research. These are phenomenology and ethnography (see Box).27

To collect data FS joined a generic TC for eight months and visited a TC plus with MG for direct observation and contact with clients, hearing their voices and living the experience. In addition, in-depth interviews were conducted with a few consultants in ID, a consultant psychiatrist in psychotherapy, and a senior therapist at the generic TC (April 2013–May 2014).

The collected data were processed by triangulating the direct observations and opinions with literature, individual and group reflection of authors in order to establish patterns and how to use them to improve the current practice. All authors are experienced practitioners and researchers with previous publications in qualitative and analytical studies in the field. As this was a service improvement project, there was no requirement for ethical approval. No patient was interviewed for this project.

**Findings and conclusions**

**Process the data**

**Suitability / eligibility assessment**

It is often a challenge to identify the right patient who would benefit from joining a TC, even if they do...
not have ID. The lead consultant in Aylesbury quotes: ‘it is almost impossible in any case to predict who may benefit from joining TC with any degree of accuracy’. Many TCs use checklists to improve objectivity of their case selection by having a ‘preparation group’ or similar pre-treatment sessions. In Aylesbury TC we used the Psychological mindedness, Ego strength, Motivation, Empathy and Linking (PEMEL) checklist, which has been developed based on the experience and expertise of our therapists and our lead consultant psychiatrist in psychotherapy.

TC staff are of the opinion that people with ID would struggle with almost all of the above mentioned criteria, as the minimum requirement for demonstrating these abilities would be the presence of language and ability to communicate feelings and thoughts. In addition, people with moderate and severe ID tend to have significant difficulty in putting themselves in other people’s shoes (empathy). People with autistic spectrum disorder, including Asperger’s syndrome, might have difficulty with this aspect, even with a higher IQ.28

On the other hand, one study has reported a high intrinsic motivation to improve in some people with ID.29 In addition, it is widely recognised that people with intellectual disabilities are able to learn the link between behaviour and reward/consequence. Therefore, the use of the PEMEL checklist to find the suitable candidates seems even less appealing in people with ID. We could not find any checklist in the literature developed specifically for people with ID.

Likewise, it is also difficult to predict who is not a suitable candidate for referral to a generic TC. However, it seems that clients with moderate to profound ID, no/limited speech or with prominent autistic features would benefit from using ‘specialised TC’ rather than ‘generic TC’.

Therapeutic communities use socio group therapy and the ‘living learning experience’. This means that accepting a member with ID could have wider implications on other members and staff as well as the client themselves. As there has been very limited (if none at all) experience of having a client with ID in a generic TC, we can only speculate about these challenges.

Client with ID
To conceptualise the challenges of treating patients with ID at the generic TCs, we can look at the functions of group therapy and expected outcome of treatment, which in this case is the formation of healthy personality. Fouks and Bion described the specific functions of group therapies as: socialising, exchange, mirroring, chain phenomena, resonance and condenser phenomena.

Given that people with ID often have multiple experiences of exclusion and isolation in their lives, it seems that they would benefit from the socialising function of TC if accepted by other TC members. However, their vulnerability might be considered as a barrier or concern. However, the anecdotal experience of one of the senior therapists suggested otherwise. She believed that communities are usually very protective of their vulnerable members.

People with ID are more likely to receive and accept information from the group they belong to18 and to mirror and learn behaviours from others. This might raise the concern about their suggestibility and mirroring of maladaptive behaviours.

The other three functions of TC are more abstract and meta-cognitive. It is more likely for people with ID to struggle with these functions and some considerations might be needed in this part to facilitate their access to generic TC.

The gradual withdrawal of psychotropic medications and other therapeutic input in the first few months is a widely accepted rule in TCs. This could have implications for people with ID who are often on polypharmacy and receive significant support from ID services. It would be probably difficult or even harmful for them to stop all of these in such a quick and unyielding fashion. Some considerations in this regard for this client group might facilitate their smooth transition to a new service. This might have some implications for other TC members as well.

Other TC members
The authors carefully observed the similarities and differences of a generic TC and a TC plus. This suggested the possibility of the following implications for other TC members if a client with ID were included in the community.

Firstly, the pace of sessions would probably need to be reduced and there may be a need to repeat some abstract concepts and links. In addition, some TC members might feel anxious about their ability to communicate appropriately with individuals with ID. This might even discourage them from giving comment or feedback to them during group activities.

The other implication could be due to extra support TC staff would need to provide for the individuals with ID. In addition, clients with ID might need to be exempted from some jobs/roles such as secretary or treasurer. Both these factors can potentially generate a sense of favouritism, which in turn would increase the risk of bullying (either way).

TC staff
Having a client with ID probably would have important implications
for generic TC staff too. The first and most obvious one is the need for extra training in communication and specific/generic issues associated with this group of clients. Communication difficulties are well known in people with ID: developing the communication skills of TC staff would facilitate therapeutic interventions in people with ID.30 There is some evidence that having a pupil with ID causes distress for the teacher and it is likely to be the same for TC staff.

One study suggested that staff cannot always expect people with ID to ‘perform’ as well as others.18 Therapists may have to be more forthcoming and direct with them: they might need to take a more active, less ‘neutral’ role. Since people with ID have some difficulties with thinking and in problem solving at the same speed as their non-disabled peers, appropriate ‘supervision’ would assist them to take decisions, resolve conflicts and avoid drifting away from social interactions. However, it will be important for staff to keep the fine balance between being forthcoming and not coming across as dominating and controlling.

The other important implication could be the role confusion. Staff need to be more proactive in dealing with people with ID in comparison with their usual clients.18 In addition, they would need to monitor and deal with the implications for other TC members such as favouritism and bullying.

Analyse the information
While we acknowledge the exploratory nature of this paper based on anecdotal experiences and personal opinions (evidence level 4 and 5), our paper is original and aligned with the current emphasis of the Department of Health to facilitate the access of people with ID to generic services and the current NHS England31 and Royal College of Psychiatrists guidance32 to reduce pharmacological interventions in people with ID.

Overall, it is the authors’ opinion that it is possible to use generic TCs for people with ID. Nonetheless, this would need some important considerations. First, the vulnerability and suggestibility of people with ID should be carefully and constantly considered/monitored by staff. This would minimise the risk of bullying and reinforcement of maladaptive behaviours. However, this could be a source of anxiety for staff and therefore an appropriate process should be considered to contain it. These processes are usually supervision, debriefing and reflection. Therefore, the senior staff, and ultimately the consultant psychotherapist, would need to have a good grasp of ID-related issues and concepts as well as staff on the ground.

This overall improvement in the knowledge and skills of TC staff could be conceptualised under the term of ‘growing of the TC’. This qualitative change would need an initial input from ID services and then gradual withdrawal of external support while the TC evolves internally.33,34

In addition, to facilitate and optimise the use of generic TCs for individuals with ID, the screening criteria for this group need to be reviewed and evolved. This could be achieved by further integration of the assessment of suitability of attending the ‘preparation groups’ where extra work on ‘emotional intelligence’ could be started and continued all the way through.

This extra work for people with ID could potentially raise the concern of favouritism and resentment in other TC members. However, this extra module on ‘emotional intelligence’ could be made available to everyone as an optional opportunity; as long as the staff bring back what happens there to the TC community, it would seem compatible with the current TC model. The same principles should apply to the difference in approach of staff toward people with ID in comparison with other members. Actually, their response and approach could already be very different toward TC members based on their individual personality traits and needs.

In summary, it seems that the initial anxiety of staff to accommodate people with ID in a generic TC is the biggest challenge that needs to be addressed if this service improvement is to be introduced. Firstly, the appropriate time to initiate any change should be chosen at a relatively stable time for the TC and ID staff. Secondly, a period of demystifying and cross-fertilising of TC and ID staff seems useful. This could be achieved through co-contributing by some ID staff to run preparation groups. This would improve the mutual understanding, skills and knowledge of both groups and, as a result, decrease the initial anxiety.

The main counter-arguments to our proposal are the threats and scepticism about the future and efficiency of generic TC itself. There are still strong positive and negative feelings toward effectiveness and the cost efficiency of this method in the current financial climate. However, NICE still recommends it as an effective therapy mode for the treatment of people with complex psycho-social problems.35

It is difficult to confidently envisage the cost and resources needed to implement this model across the country due to significant heterogeneity of current therapeutic communities and their current resources. Although our anecdotal observation suggests that the costs should be nominal because a change to staff’s attitude and addressing their anxieties, are the main steps toward the successful implementation of the model.

It is also important to acknowledge the possibility of teething
problems and unforeseen issues, for example, about the withdrawal of psychotropic medication in people with ID. These issues could be thought through the ‘living learning experience’ at the TC.

A carefully designed pilot implementation of our model in one or more TCs would be the next logical step. Such pilots should aim to study the qualitative impacts on staff, patients and other service users as well as measuring quantitative indicators of its effectiveness (such as the need for psychotropic medication, number of challenging behaviours, etc.). The vision is integrated and routine access for people with intellectual disability to mainstream TCs across the country where staff and service users feel competent and/or empowered to work effectively with this deprived group of clients.

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Declaration of interests
No conflicts of interest were declared.

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