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Review

The Institutionalization of People with Intellectual Disabilities: A Never-Ending Story

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Abstract: The institutionalization of people with intellectual disabilities has been a common international response across cultures and generations that persists to this day. This chapter recounts its inheritance and manifestation in modern service provision. An institutional mind-set persists among clinicians and managers despite policies that emphasise the rights of persons with intellectual disability and anti-discriminatory practice. Alternative provision is rooted in person-centred practice; with a growing body of evidence for the improved quality of life that results from it. A reflective activity encourages readers to examine a recent case when they were associated with an institutional placement and what alternatives might have been sought. Yet alliances with other professionals, self-advocates and family carers will be needed to effect real and lasting changes in our service cultures and even then, the long shadows of institutional care may still persist.

Keywords: Intellectual disability; institutions; medical model; rights; person-centred; quality of life

Our Inheritance

For centuries around the world, people who were different – whom today we recognize as intellectually disabled[1] – were ostracized within their tribes, clans and communities. They were shunned as harbingers of misfortune who brought shame on their kin. Or possessed by evil spirits that could not be exorcised. Many did not survive into adulthood as they succumbed to infanticide, childhood diseases and malnutrition. The survivors though faced a pitiful future, often ending up as outcasts and beggars (Roth et al., 2019).

The industrial revolution across the western world and England in particular, sucked many people into the emerging cities and factories. Those unable to be productive workers often ended up in the 'workhouse'; the precursor of the institutions that were to follow. In those years, no distinctions were made about the different "afflictions" besetting the unemployable, "vagrants" and "lunatics". The priority however was to get them off the streets and reduce the threats they posed to responsible citizens. Prison provided only a short-term solution. The more enlightened medical doctors successfully argued for the opening of special hospitals – "lunatic asylums" - for those who were assessed as 'mentally disordered' through illness and/or disability (Bewley, undated).

Such institutions had a dual function. They provided a haven of safety for the persons where they might receive 'treatment' while at the same time protecting the wider public from any dangers the "patients" might pose. Their location away from the cities reduced the risk of contact. In later years the number of patients living their lives in institutions increased markedly as they became differentiated into those with mental health conditions and those who were deemed to be "idiots" from birth. These institutions persisted for more than 100 years. They were copied in many other countries throughout the British Empire, the United States, continental Europe and Soviet Russia guided by medical and nursing staff, local and national politicians, religious orders and many other

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[1] Other terms in past and present usage include: mental deficiency, mental retardation and learning disability

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charities. For nearly 100 years it was THE model of care for persons with intellectual disability (Walmsley & Jarrett, 2021).

But the aspirations of institutions being a place of healing and asylum for people in need was subverted by inadequate funding, poor management, low morale and ultimately squalid working and living conditions (Morris, 1969). One eminent visitor wrote in 1965 of people "living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo." The person was Senator Robert Kennedy on a visit to Willowbrook, a state-run school for people with intellectual and developmental disabilities in Staten Island, New York.

In due course, whistleblowing by staff, media reports and public inquiries revealed the extent of the deprivation and abuse perpetrated in institutions. The move to close institutions then became a policy objective of many countries but it has been a slow and incomplete process and to this day, institutions and institutional thinking remain in many countries around the globe (Scoir st al. 2020). And while their physical presence may have diminished, the forces that drove their creation and modes of working still live on; notably in the hierarchical model of medical care led primarily by psychiatrists and nurses, and which other professions have emulated In this chapter, we will explore why the closure of institutions is a never-ending story with no happy conclusion as yet. It is a reality to which psych professionals collude despite their rhetoric about human rights and evidence-based practice. And one that society tolerates because old fears and stigmas lie deep in our beliefs of what it means to be intellectually disabled (O'Hara and Bouras, 2007).

Present Day Institutions

The old mental institutions and long-stay hospitals that housed many hundreds of thousands of people with intellectual disability in their hey-day, have long been emptied and the sites repurposed. But buildings do not define an institution, although their design and location did resemble a prison more so than a home. Rather the malign features of the institution were the crowding of people into communal dormitories, bathrooms and living areas, the rigid daily regimes, constant supervision, the lack of privacy, absence of choice, suppression of individuality and often the threat or use of punishments, such as seclusion in locked rooms.

Of course, there were some positives. People's needs for food and shelter were broadly met, illnesses were treated, friendships were formed, and most staff were caring and loyal workers. But these positives could not outweigh the malign influences associated with congregating people with diverse needs and personalities into constrained spaces and limited opportunities for personal expression through recreation, education or productive work. Hierarchical authoritarian management systems supervised the daily work of staff who were often lowly paid and undervalued.

Institutional practices have lived on in new guises and are not confined to people with intellectual disabilities. Residential and nursing homes, catering for upwards of 20 and more persons retain many institutional features (Cienkus,2022; Hatton, 2017). These congregated living arrangements are favoured for those with higher dependency needs and persons with dementia but residents with intellectual disabilities enter younger and could spend many years in such homes due to the beneficial health and social care they receive. Once admitted they rarely leave.

Group homes became a preferred approach internationally to resettling residents from long-stay institutions and for people moving from family care (Braddock et al, 2001). Cost savings were gained by having larger establishments with up to 10 people living in the same house, albeit with their own bedroom but sharing all other facilities. Many residents had no choice over whom they lived with, nor could they easily move to another location. Paid staff came on a rota basis to support and supervise the residents but with insufficient time to focus on individuals while managing all the household tasks. Group homes also run the risk of becoming mini institutions with fixed routines to maintain to keep everyone in order.

Latterly, 'assessment and treatment units' were created to meet the needs of persons identified as having behavioural and/or mental health issues. People were admitted from family homes or residential facilities when they could no longer be managed in those settings and especially when they posed a threat to themselves or to others – notably co-residents or staff. The Units tended to function like a mini hospital with 'treatments' provided by doctors, psychologists, therapists and nurses. But even in the best-resourced units, the treatments often did not produce the intended outcomes in a timely manner, resulting in delayed discharges which were compounded when patients could not be returned to their previous abode. The Units became a new form of long-stay hospital (MacDonald, 2017).

Alongside this specialist provision, a sizeable proportion of people with intellectual disability have been and are regularly detained in prisons (García-Largo et al., 2020; Murphy et al, 2017). Estimates of the numbers vary widely across jurisdictions but often their condition is not recognized or responded to within the prison and the wider criminal justice system. For most, prison will not be their long-term abode but on release they often experience the same fate of the homeless; drifting between rough sleeping and hostels with increased risk of petty crimes and drug abuse.

Institutional practices can also live on in special schools – especially those which offer boarding arrangements - and in day centres and workshops catering for large groups of adult persons (McConkey et al., 2017). Nor are other care arrangements immune from institutional practices such as respite breaks and domiciliary care.

So, what explains the persistence of institutional care arrangements for persons with intellectual disability? The most common arguments stress economic considerations such as shared costs across groups, the convenience for staff of having people in one location, and ease of supervision of both staff and residents. These justifications are further bolstered by comparison with how services are delivered to other client groups, such as care of the elderly and issues around prioritizing competing needs for scarce funds in health and social care. In sum, congregated care arrangements are seen to benefit the overall care system rather than the people who use them. But perhaps there are deeper reasons for a continuing reliance on institutional models, what we could call a mindset*: "a habitual or characteristic mental attitude that determines how you will interpret and respond to situations"* [2] (Pelleboer-Gunnink et al, 2017).

The Institutional Mindset

When faced with decisions about the care of 'difficult' or 'complex children or adults with intellectual disabilities' especially but also more generally, it seems there is a bias towards institutional solutions. Psychiatrists and psychologists are not immune from such biases, despite their pledge to do no harm and to always act in the best interests of their often called 'patients'. Several influences come into play and although they are presented separately below, they interact, each influencing the other which makes it more difficult to appreciate and to reduce their possible malign effects on placement decisions and intervention strategies.

The Medical Model of Disability Lives On

Despite the international recognition of the social influences underpinning the functioning of persons with disabilities as manifest in the World Health Organisation's (2009, updated 2018) International Classification of Functioning, Disability and Health, many service models are still predicated on assessing and reducing the person's impairments. This results in specialist assessment and treatments delivered in clinics, schools and medical centres by discipline specific experts. For their convenience, it is deemed better to gather them and their 'patients/clients' in one location with little attention paid to the wider social-environmental influences on the development and behaviours of their 'patients' and which may well have contributed to the extra support they may now require.

Implicit in this approach is that people with a common impairment - will benefit equally from commonly delivered interventions such as pharmaceuticals or Behaviour Therapy. Admittedly an evidence-base may exist of the effectiveness of the chosen treatments but there is no guarantee these are equally effective across patients with differing life experiences. Moreover, if the treatments are

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[2] "Mindset." Vocabulary.com Dictionary, Vocabulary.com, https://www.vocabulary.com/dictionary/mindset. Accessed 14 Sep. 2023.

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delivered in specialised settings, the risk is that any gains may not transfer to the person's everyday life at home and in the community. Which begs the question why is the intervention not attuned to, and delivered in such settings?

Disabled People Do Not Enjoy the Same Rights as Their Non-Disabled Peers

The United Nations Convention on the Rights of Persons with Disabilities (2006) was the international response to a widespread conviction that a disability made a person less than human and that they did not deserve or were incapable of having the same rights as their non-disabled peers. The fact their rights had to be specified was in itself recognition of a denial of their rights. But United Nation Declarations or national policies and laws, do not change the mindset and behaviours of long-established service systems such as those which persist in modern education and health services. The rights to employment of people with intellectual disabilities (rather than attending day centres) or to have their own accommodation (rather than group living) are downplayed in favour of what has been traditionally provided and hence will continue to be available unless cultures and systems embrace a rights-basis to service delivery (Perlin, 2018).

Protecting Others Outweighs Protection of the Person.

People with severely challenging behaviours of all ages pose a threat to the wellbeing of others around the individual, such as family members, paid caregivers, professional staff and, albeit more rarely, the general public. A risk assessment will confirm the need to remove the person from their present setting as part of their duty of care to other persons to whom the person poses a threat. Were they not to do so and something untoward happens to the third party, then their managers, as well as the legal system, even the media will accuse them of negligence and call for possible sanctions. In these instances, a speedy dispatch of the person to more institutional settings often occurs with the person legally detained under Mental Health orders if they do not go voluntarily. This decades old tradition places protection of others above protecting the individual from further harm.

But just reflect on the possible harm a person may face when removed to different settings An abrupt change occurs in their living arrangements away from familiar care-givers and friends, disruption of their formal and informal supports, familiar routines abandoned; all of which often results in increased stress and anxiety, especially for those on the autism spectrum (Quinn et al., 2022). Perhaps the biggest irony is that they may be placed in settings where there are others with challenging behaviour from whom they are at risk of harm or whom they may harm. In such settings there is a greater risk, some may say *need* to use seclusion, restraint, medication and withdrawal of privileges. All of which seems more like punishment than therapy and their accommodation becomes more like prison than place of healing.

Group-Based Services are Cheaper

On the face of it group-based services make sense; our school systems being a prime example. Pupils are organised into groups largely based on two considerations: what monies are available to spend on schools and a judgement as to the outcomes achieved. Would classes of 15 pupils produce better outcomes than those with 25 pupils? However, this balanced logic is largely absent in disability services mainly because attention has been focussed solely on costs with scant attention given to the outcomes for users of services (Cronin & Bourke, 2017). Instead, service planners and providers have persisted in funding high-cost, group-based service models without assessing their value-for-money or seeking additional funds to ensure better outcomes for the users. More often they have done the opposite by reducing funds for services without considering that poorer outcomes may result.

The person Can't Object

Most people with intellectual disability are not verbally proficient and cannot marshal arguments against decisions made by those who are perceived to be cleverer than themselves. Family carers and junior staff in services may feel similarly. But even when challenged, professionals may feel affronted that their advice is being questioned, especially when they have few or no alternatives to offer, compounded by a lack of time to listen or for negotiation.

More generally, the discrimination faced by persons with intellectual disability has not been matched by the vigour and consistency that challenged the discrimination experienced by women, people of colour, sexual orientation, ethnic and religious minorities in our societies and services. The unconscious biases around discriminating practices remain even though the managers and professionals in health services espouse the language of equality for all (Shogren, 2022).

What Needs to Change?

To be clear, there are times when institutional care is indeed in the person's best interests. Rather my point is that this choice – indeed all professional choices - have to come after a process and that an institutional response should never be the first and only choice that is considered.

In more affluent countries, institutional care is fortunately on the decline. In poorer countries the challenge is preventing its emergence. The shift from institutional care has been fuelled mainly by the advocacy of people with disabilities and their allies, notably parents of children who argued and fought for their sons and daughters to have a normal life. Changes in government policy and services were assisted by the scandals uncovered in large institutional settings which sadly continue to be repeated in more modern congregated settings now called assessment and treatments centres or nursing homes (Lodge, 2021). Regrettably, professionals such as medics, nurses and psychologists were the most vocal for the retention of these options (Linker, 2013).

The insights gained from successful de-institutionalisation can guide current efforts to avoid the tendency to fall back on institutional responses. In essence it involved a deep commitment to plan for each person individually.

Person-Centred Planning

Person-centred planning may have become a cliché but nevertheless the process for avoiding institutionalised responses is a simple but as complex as that. It's complex because existing systems have to be shut down and person-centred ones grown in their place. Experience tells us that the rhetoric from policy-documents does not readily transform services nor will those gaining a livelihood from institutional provision willingly transfer their income to other forms of provision. Neither has the advocacy of and for persons with intellectual disability been sufficient to bring about the radical changes required. Caught in the middle have been well qualified professionals – psychiatrists, psychologists, therapists, nurses, social workers, paediatricians – whose collective voices often have been muted with respect to reform possibly because they have been reluctant to challenge the managerial inertia around service reform (Perlin, 2018).

The challenge from professionals can take different forms but arguably the most effective is to promote tenaciously the welfare and best interests of the common people. In Victorian England, Florence Nightingale used it to transform hospitals, William Rathbone to instigate district nursing and Octivia Hill, to found what we today call social work. Similarly, the closure of institutions for people with intellectual disability had visionary leaders whose persistence and determination brought about the swift closure of many hospitals (Beadle-Brown et al., 2007).

So, what can professionals do to effect change? Here are the key strategies that have proved to be effective, especially when used in combination (Eklund et al., 2019; McGill et al., 2020).

Know the Individual

Central is to plan what is best for the person. This means listening, observing and discovering each individual's experiences, aspirations and needs and doing this in the settings which they currently live. There are various tools available for obtaining and documenting the information gathered (National Development Team for Inclusion, 2020). Admittedly this process can take some time but in essence the goal is to find out what is important for the person, what they like and don't like and similarly who are the people that are important in their lives. More detailed gathering could be entrusted to persons who know the person well and have done so for some time. Importantly the plan explicitly identifies the outcomes to be attained for the person. These form the basis for evaluating the effectiveness of the planned actions.

Multidisciplinary and Cross Sector Team Working

The lack of joined up working across the various professionals involved in the person's care is a longstanding complaint and which could be avoided if multi-disciplinary - or better still transdisciplinary - working became the norm (Castro-Kemp and Samuels, 2022). Small teams of core professionals seem to work best and are easier to manage but the membership should be determined by the person's aspirations and needs. Modern technology allows for meetings to happen virtually and for information to be quickly shared. One named person should be the co-ordinator for the individual. Decisions should be made through consensus as far as possible, but the most senior person - based largely on peer recognition or on rotating the chairing role at meeting - may have to take responsibility for a decision, documenting clear reasons for its choice.

Options and Choices

Exploration of the options that are currently available or could become available is a necessity. Engage with the person and their advocates as to their preferences. Facilitate visits to different options as well as scrutinising websites, videos and booklets. Undertake an option appraisal and if no existing service is available then engage with management in devising a new service tailored to the individual but likely one that will also address the unmet needs of others.

Range of Pathways and Gradations of Services

Following on from the above, the team of professionals should develop a pathway through the various options that can or could be available across the relevant sectors, such as health, housing and day-time occupation (Royal College of Psychiatrists, 2014). Moreover, the pathway can also illustrate how differing needs will be met through having different tiers of service, from least to most intensive. Charting these pathways can illustrate the gaps in current services especially the preventative actions that can be taken to avoid triggering referrals to a 'higher tier' of service. The pathway approach also enables costs to be determined for services across the tiers so that value-for-money analyses can be undertaken when costs are set against outcomes.

Mobilising Informal Supports

Professional services need to look beyond their own resources if they are to have an impact on a person's overall quality of life. Connecting with the community and voluntary sector will open up options around informal supports for the individual through leisure and sports activities, voluntary work and membership of social clubs with the potential for developing networks of acquaintances from which friendships might merge. Similar activities can also be enjoyed by groups of people with intellectual disability where friendships and romantic relationships have also developed (McConkey and Lorenzo, 2022).

New Professional Support Roles

Workforce planning in intellectual disability services is still dominated by outmoded service models with more investment going to highly trained and paid professionals whose engagement with service -users is for short consultations for a limited time whereas the support workers who have up to 24/7 contact with service users are the least qualified and lowest paid. It is long past the time for rebalancing the professional workforce away from the former to the latter (National Quality Board, 2018). This will mean new forms of training and accreditation opportunities to enable new cadres of support workers to take on greater responsibilities in meeting the needs of people with intellectual disability and their family carers through personalised provision and in community settings. Salary scales will then need to reflect their increased responsibilities and expertise but even then, many more persons of this grade can be employed from current health spending on well paid professionals and clinicians.

Self-Directed Support

A major innovation in social services that has also been trialled in health services, has been to allocate the funding of service supports to the person themselves so that they choose the supports and services best suited to them, for example a personal assistant for daily living tasks (Morrow & Kettle, 2021). The principle is fine, but the administrative procedures associated with it have blunted its use and effectiveness, especially for people with intellectual disability most of whom will need a broker to manage the payments. Also, to maximise the effectiveness of self-directed support, ideally the fore-going strategies need to be in place, otherwise the range of supports available for purchase by individuals will not be available.

Making the Seemingly Impossible, Possible

The foregoing strategies can seem impossible to attain with many factors working against them. Worn down family carers will take whatever option is available and have no energy to explore alternatives. In cash-strapped services, energies are directed at maintaining current service provision with little appetite to embark on their transformation. Visionary professionals are fearful of raising the expectations of people with disabilities that may not materialize. In poorer countries, these factors combine to ensure little changes and unmet needs continue to grow. Sadly there are no quick fixes other than one; change comes not in giant leaps but one step – one person at a time. Foot soldiers rather than generals can bring about change.

Changing the Singer and the Song

In this final section, I want to challenge you. I have outlined how the 'song' around institutionalisation needs to change. But that cannot happen without changing the singers – that may include you! I will assume that you might be a lone voice singing "the times they are a'changin" although I suspect that if you start to openly question existing practices you will find liked-minded people to join the choir. But again it has to start with one person – you.

Think about a person you have recently worked with for whom the decision was their admission to a congregated setting for either a time-limited placement or an extended stay. It might have been to an assessment and treatment unit (in area or out of area), a nursing or residential home, a special school (day or residential) – see earlier section for other examples. Use the pro forma below to reflect on the factors that lead to that decision and ones that on reflection you might have neglected to consider.

	I did this	**I could have done this**
Assessment of the person's problems		
Assessment of the person's social and environmental context		
The risks the person posed at the time		
The risks the person could be exposed to in the new setting		

The person was involved in making the decision		
Who advocated for the person?		
I took account of the Person's rights (e,g informed consent, assisted decision making services)		
I investigated other options		
Other colleagues were involved in the decision.		
I detailed the outcomes that the placement would/should provide		
Systems are in place to ensure the outcomes are being monitored or achieved.		
I am hopeful that the person now has a better quality of life and I am seeking evidence of it.		
Any other comments and thoughts?		

If you can find a colleague with whom you can discuss your responses, it may give you further insights.

Also, if you repeat the exercise but this time for another patient/client for whom a congregated placement was avoided, that might also illuminate the influences on your decision-making.

The table below is an opportunity to highlight the key points you took from this exercise and how you might act differently.

Summary	**Your response**
In retrospect was this a good decision you and/or others made? Note the reasons for your answer.	
What would you like to have done or would do differently?	
What stopped you from doing the above?	

What have you learnt from this exercise?	

A Never-Ending Story?

Knowing what we can be done to avoid institutional care is no guarantee that it will happen. Rather circumstances and events may make it unavoidable as the 'least worst' option. Those particularly at risk are persons with the most complex needs for whom our best staff struggle to provide the interventions required to meet their needs. But it is not just a few persons who are affected but other pressures threaten many more. At present in the United Kingdom and other countries, the factors sustaining institutional care are a lack of trained staff, increasing numbers of people requiring services and cost pressures within health, social and educational services. The business solution is a return to group-based options despite their known imperfections and poorer value of money in terms of outcomes for the service users with the clinching argument being that in a crisis, any type of support is better than none. Professionals and the organisations that represent them, can collude in maintaining imperfect models of care through an unwillingness to opt for alternatives over which they will have less influence. Their power as decision-makers will be ceded to others even though intellectually they can knowledge the force of arguments for moving away from institutional models of care.

Admittedly too, there are family carers and some people with disabilities who take comfort from institutional provision for the security and continuity that it offers whereas newer forms of service are perceived as involving too many risks while discounting the opportunities they could offer to the person.

And what of individual professionals such as psychiatrists and psychologists? Do they accept the constraints imposed on them by their business managers and the preferences of family carers when they know it may not be in the best interest of their clients based on their clinical judgements and research evidence? But how best can they challenge the system? I suspect local solutions will be needed rather than national plans coupled with persistence and support from allies.

Alas for all these reasons I suspect that we will not see a speedy end to institutional care and may never do so, much as it pains me to say so. Yet I take hope, knowing that services have changed remarkedly in the past decades and can do so again. I hope too a future generation - you included - will prove me wrong and that your advocacy, creativity and ingenuity will confine to history the long shadow of institutional care practices.

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