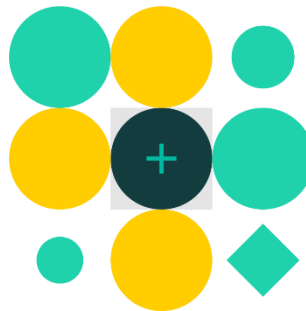


Case studies on international policy and implementation – Case 6

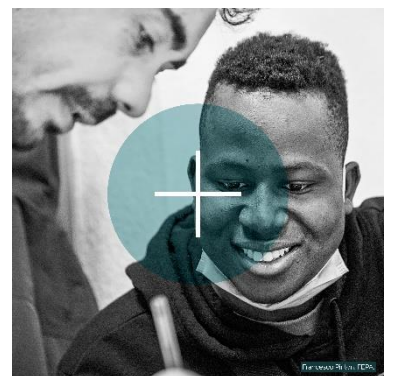
Deinstitutionalisation of People with intellectual Disabilities in Wales



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Estrategia estatal
de desinstitucionalización

Para una buena vida en la comunidad

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The logo for BILD (Behavioural Inclusion and Learning Disabilities) features the word "bild" in a bold, lowercase, blue sans-serif font. A small blue circle is positioned above the letter 'i'.

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Key messages

Deinstitutionalisation requires massive change in knowledge, practice, and culture. There needs to be agreement and, therefore, clarity on what the preferred accommodation models are, not just in terms of size and location but also in terms of management and staff practice. Research evidence supports domestic-style, small-scale ordinary housing based in people's local communities, combined with attention to what staff do in practice including person-centred support focusing on developing people's skills and abilities and participation in meaningful daily activity, prevention, early intervention, social integration, the promotion of well-being and co-production. This is likely to minimise the danger of transference of institutional practice into new service models and promote the development of Capable Environments.

To maximise success, it is advisable to establish some carefully constructed pilot services to test out theoretical models and to allow opportunities for key stakeholders to have direct experience in establishing new services and gain knowledge of what is needed to adapt new models best within the Spanish context. It is likely that systems such as policy, funding, legislation, and regulations will need to change to support deinstitutionalisation. This will enable better widespread implementation of the best quality models, avoiding some of the problems experienced in the UK and elsewhere.

Ensure funding structures support the development of preferred models. Focus on non-profit, third sector social enterprise-type initiatives. Research findings and our own experience have shown that some private, profit-making organisations have made considerable amounts of money, profiteering from government funds while providing very poor services for vulnerable people. Funding should also be based on individual assessment of each person's needs rather than any pre-set categories that carry specified amounts of funding irrespective of actual need.

Attention needs to be paid to the quality of mainstream services developed for all people with intellectual disabilities, with sharp focus on staff training, staff competence and effective management support, including practice leadership. Poor quality in mainstream services generates problems that require more specialist and expensive remedies. Research in Wales has shown that much work undertaken by specialist challenging behaviour services is in addressing basic service deficiencies in mainstream services rather than being of a specialist nature.

People with more complex disabilities, including challenging behaviour, need to be specifically included in deinstitutionalisation plans from the start. Placing these people in separate services, away from their local areas means that the skills required to support them may never be developed within mainstream community services. In the UK, we are still seeing the results of this type of policy: the majority of recent scandals have involved people with complex needs placed in privately run, often isolated, profit-making services that emulate the worst traits of institutions.

Better support needs to be developed for families, including funding made available directly to them which gives them flexibility in deciding what support they need. This is likely to encourage co-production and avoid sudden breakdown and unplanned admissions to unsuitable establishments.



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1. Introduction

Deinstitutionalisation in Wales began in earnest just over 40 years ago and, although progress has often seemed slow and much still needs to be achieved, the situation of people with intellectual disabilities, social attitudes, family and individuals' expectations and patterns of service delivery have undergone dramatic changes. The arguments in favour of deinstitutionalisation have been won and the focus has shifted onto the details of community-based service delivery.

The authors are fortunate to have worked in intellectual disability research and pioneering service development since the late 1970s and witnessed many of these changes directly. To summarise the deinstitutionalisation process and key lessons in a brief paper necessarily means that much has had to be omitted. While we have included some of the most significant historical events that led to the deinstitutionalisation movement, the following is based on our thoughts at this time on the key stages and messages relevant for Spain.

2. Historical milestones towards deinstitutionalisation

The Mental Deficiency Act (1913) first highlighted the need for services for people with intellectual disabilities: at this time segregated, isolated institutions run by local authorities were considered the most appropriate, with admission usually for life. Responsibility for such services shifted to health after the creation of the National Health Service in 1948, but services continued to be segregated from services for the general public.

Various attempts to shift the emphasis to integrated, community-based models of residential and day care were made during the 1950s and 1960s (cf. Royal Commission, 1957; Mental Health Act 1959) but little or no progress was made. Families remained largely unsupported, the long-stay hospitals were becoming overcrowded and people with intellectual disabilities continued to be segregated from normal patterns of life. Then in 1969, whistleblowers¹ exposed the first public scandal, where the deprived and inhumane conditions that had developed within the institutions were publicised in the media, causing a national outcry (DHSS, 1969).

The conditions within institutions were further highlighted by an influential Government White Paper (DHSS, 1971) that contained a programme of action to improve services, encourage joint planning between health and local authorities, shift care from hospital to the community and emphasised the rights of people with intellectual disabilities to develop skills and abilities and enjoy normal patterns of life unsegregated from society.

An important influence on the meaning and substance of community care at that time was the widespread acceptance of the **Principle of Normalisation** (Wolfensberger, 1972). Included in this approach was an emphasis on services responding to individuals' needs in ways that respected their dignity as well as promoting their growth and development, and the recognition that services should be provided in the least possible

¹ Staff members who report wrongdoing or malpractice



restrictive settings. An important consequence of this philosophy is that it helped to focus attention on the values and principles which underpin community care policies and, therefore, the development of new service models.

The gradual change in values that occurred following these influences created a shift in service objectives from the provision of custodial to habilitative care, with an increasing emphasis on individuals' quality of life. Initial reforms focused on the development of alternative forms of residential care, characterised by smaller sized settings, location within communities, higher staffing levels, with service aims based on the promotion of independence and on social support rather than medical care.

Early developments were intermediate models such as hospital units with some domestic-style aspects (Felce, Kushlick and Smith, 1980). These were superseded by a series of innovative 'first generation' community-based pilot projects, such as the Andover Project in the South of England (Felce, 1989) and the **NIMROD** Project in Cardiff (Lowe and de Paiva, 1991). These demonstrated the feasibility and beneficial outcomes of providing residential care for adults with the most severe intellectual disabilities in ordinary housing built for the general population indistinguishable from neighbouring properties, a concept supported by the influential Kings Fund Paper '**An Ordinary Life**' (Kings Fund, 1980).

Subsequent community care policy during the 1980s continued to develop around the themes of meeting individuals' needs through the provision of a balanced and flexible range of community-based, integrated services. In Wales, the policy objective was radical service reform, based on developing the non-profit or third sector to provide alternative care in ordinary housing and prohibiting the development of any settings for more than six people (Welsh Office, 1983). By 1990, this policy had achieved new places for nearly one thousand people across Wales.

The usual expectation is that projects developed after successful pilots would achieve improved outcomes as technologies are further refined in the light of experience. However, this was not the case in these 'second generation' ordinary housing services. The main focus was on location, size and staff ratios and, in marked contrast to Andover and NIMROD, little attention was given to what staff should do to support the people, the associated practical training staff would need or the desired outcomes for the people being supported (Felce and Perry, 1995). Studies examining deinstitutionalisation effects across these 'second generation' services found few or only variable benefits in behaviour or quality of life outcomes (see Emerson and Hatton, 1994), emphasising that **simply changing the setting was not enough to improve quality of life**. The key evidence from research demonstrated that, while ordinary housing and adequate staffing are prerequisites for quality, essential components to take full advantage of the move to community settings also included the appropriate management approach, staff supervision and, most importantly, direct support to enable people to participate in activities associated with living a typical life (Felce, 1996).

These findings prompted a call for a re-introduction of the approaches used in Andover and NIMROD, subsequently named the **Active Support Model** (Jones et al, 1999). This approach comprises: a model of interaction to teach carers how to give graded levels of help to enable people to participate in daily activities; planning tools to organise a full



range of activities associated with a typical lifestyle as well as the support needed; and a simple way of recording progress so quality can be monitored, and improvements made on the basis of evidence. Multiple research studies within Wales and wider afield have demonstrated that training or retraining staff in this model can achieve similar beneficial outcomes as demonstrated in the original pilot services (Toogood et al, 2016; Flynn et al 2019). A more recent development of this approach is **Capable Environments** (McGill et al, 2020) which includes participation in daily activities among twelve elements it considers essential to the provision of high-quality support.

3. Behaviour problems (challenging behaviour)

The lack of expertise amongst staff in these 'second generation' services meant that people with less severe disabilities and with no challenging behaviour were typically the first to benefit from deinstitutionalisation (DoH, 1989). The remaining institutions continued to house an increasingly disabled population, with challenging behaviour continuing to be a primary reason for new admissions and re-admissions following community placement breakdown. The recognition that the skills and aptitude to work therapeutically with this group constitutes a specialism led to the creation of Assessment and Treatment Units (ATUs) with the aim of developing separate therapeutic environments capable of transferring individuals to mainstream services after a temporary stay. However, two key limitations of this model emerged:

- Firstly, any desired behavioural change achieved in one setting were unlikely to be generalised to a new setting.
- Secondly, the continued lack of competence in mainstream services created a barrier to discharge from ATUs, leading to intended short-term stays becoming long-term placements thereby defeating the original objectives of this model (Newsom and Emerson, 1991).

To overcome these limitations, a new direction for providing specialist assessment and treatment expertise emerged during the 1990s, in the form of peripatetic support teams. These were multi-disciplinary and aimed to provide intensive, individually tailored support to people in their usual home environments, as well as individually tailored, specialist training to their carers in how to support people. Their aim was to effect desirable change in the behaviour of the people and of their carers in their home setting, thus increasing the likelihood that improvements would be maintained after intervention ceased (Lowe et al, 1996). This model has been sustained but continues to suffer similar limitations to the ATUs in that turnover of cases can be slow and long-term impact relies largely on the capabilities within the mainstream service settings.

A parallel development at this time was the development of ethical, pain-free methods of physical intervention to help staff manage incidences of violent behaviour safely, prevent further escalation and reduce injuries among staff and the people supported. This type of training originated in Wales, spread across the UK and was accredited by the British Institute for Learning Disabilities in consultation with the Department of Health, the Department for Education and Employment and the Health and Safety Executive (BILD, 2006). The BILD Code of Practice included guidance on policies, best interest criteria, techniques for physical intervention, and health and safety, and professional conduct.



Over the last 20 years there has also been an increasing emphasis on proactive strategies that prevent or reduce the likelihood of challenging behaviour occurring, thereby reducing any need for physical intervention. **Positive behaviour support (PBS)** (Gore et al, 2020) is a person-centred framework for providing long-term support to people who have, or may be at risk of developing behaviours that challenge. It is a blend of person-centred values and behavioural science and uses evidence to inform decision-making. It is based on the understanding that behaviours that challenge happen for a reason and may be the person's only way of communicating an unmet need. PBS aims to understand these reasons to meet people's needs better, and enhance their quality of life to reduce the likelihood that the challenging behaviour will happen.

Despite the understanding of the skills and knowledge needed, and general improvements in service quality, the UK continues to see scandals demonstrating poor practice such as the events at Winterbourne View, a privately-run **Assessment and Treatment Unit** (see Bubb, 2014). Indeed, numerous Government and professional reports have highlighted that people with intellectual disabilities and challenging behaviours are vulnerable to abuse, and are more likely to be placed in private residential and hospital settings that often generate major concerns around quality and safeguarding, very similar to the old institutions (DoH, 2014; 2007; National Audit Office, 2017; National Development Team for Inclusion, 2010; NHS England and LGA, 2014; NICE, 2015; Royal College of Psychiatrists and the British Psychological Society, 2016; Skills for Care and Skills for Health, 2014).

The public scandals have usually occurred in isolated services for people with the most complex needs, supported by staff with little or no training and distant management. Another common characteristic is that the people supported were difficult to place locally, close to their natural social networks, which highlights continuing lack of expertise in many mainstream services. The over reliance on restrictive practices used with these vulnerable people has been a growing concern, highlighting the need for specialised PBS training to be far more widespread across social care and all sectors. There is also an increasing recognition that restrictive practice goes far beyond mere physical restraint but includes such practices as isolation or segregation, social distancing, humiliation, sedation, forced activity, forced disengagement, withdrawal of rights or privileges, cancellation of preferred activities, or any other method of control that causes the person distress or discomfort.

The most recent response to this is the establishment of the **Restraint Reduction Network (RNN)**, an independent network which brings together committed organisations in education, health and social care, based on the recognition that, whilst restraint may, on rare occasions, be necessary to keep people safe, it is always traumatic and infringes human rights and must be minimised in therapeutic settings (Ridley and Leitch, 2019). All RNN work is directed and informed by the voice of people with lived experience of restrictive practices and their families. The Network shares learning and develops quality standards and practical tools that support reduction of restrictive practices and has increased focus on restraint reduction across health and social care. Agencies are invited to sign up to the Network by agreeing to develop structured plans for reducing restrictive practices for each person they support for whom any such strategy is prescribed.



Physical intervention training is now accredited by RRN standards, and new rules require any physical intervention training to be accompanied by training in preventative approaches such as PBS or trauma informed care. This means that physical intervention can no longer be taught in isolation.

4. Staff training and maintaining quality

Much has been learned about staff training over the last 40 years. Traditional methods relied solely on classroom instruction with misguided assumptions that learning would be generalised to the workplace (Stokes and Baer, 1977). Training in simulated work settings was found more effective (Reid, Parsons and Green, 1989), with training in the actual workplace being the logical next step (Anderson, 1987). For hands-on practitioners, which includes direct support staff, there is a growing evidence base to suggest that the most effective training is achieved through a **three-stage model** which incorporates all these aspects: classroom-based teaching to provide the theoretical knowledge; role play in simulated settings to allow practice of skills in a safe environment, and in-situ interactive training to support the development of practical skills in the natural workplace (see La Vigna et al, 1994).

There is ample research to suggest that this form of training, such as used in the **active support model** (Jones & Lowe, 2013; Jones et al, 2001; Jones et al, 1999; Toogood et al, 2016; Flynn et al 2019) is more effective than traditional didactic teaching. A further crucial characteristic of this training model is that, rather than simply being delivered for a set period irrespective of achievement of competence, the in-situ stage continues for each staff member until they meet predetermined performance criteria. This model ensures that staff become competent in the required skills and are able to put them into practice. We should hardly be surprised by the need for this type of training, as similar methods are commonplace for other practice-based professions such as musicians, doctors, lawyers, nurses and so on, but are still relatively new to the care sector. In recognition of the need for standardisation of such training to ensure quality, the PBS academy, an association of professionals and academics, helpfully drew up a comprehensive set of training standards as guidance (PBS Academy, 2017).

It is important to emphasise that training also needs to be considered within the context of a workforce development approach and supported by the culture of an organisation, its infrastructure, policies and procedures. Furthermore, improving staff performance requires not just initial training, but ongoing coaching in the workplace through **practice leadership**. It is insufficient to assume managers will automatically undertake this role as many are distanced from close attention to working practices due to heavy administrative duties or responsibility for multiple or geographically dispersed settings. Practice leaders need to fully understand theory, and guide implementation through role modelling, working alongside staff on a regular basis to observe, support and provide feedback with the aim of reinforcing desired performance and identifying potential barriers to implementation (Beadle-Brown et al 2014; Bould et al 2018; Osgood,. 2022,). The establishment of practice leaders can help achieve the cultural change necessary for high quality service provision, and so this essential part of workforce development cannot be overstated (Denne at al., 2015).



A further role of practice leaders is helping to monitor the ongoing quality and effectiveness of service delivery. A useful service quality assurance tool is **Periodic Service Review (PSR)** (La Vigna et al, 1994), which records progress toward meeting individual client objectives and can also be used to assess the outcomes and quality for whole services or specific service elements. PSR has four core integrated elements: performance standards, which operationally define service processes and outcomes; performance monitoring, which measures the extent to which desired outcomes are being achieved; performance feedback, which provides regular positive feedback to all staff in relation to their achievements against service targets, such as those detailed in an individual's PBS plan, and staff training, where any areas of required training are identified to improve performance. PSR has been welcomed by staff as a quality monitoring tool that supports improvement in services for people with challenging behaviour (Lowe et al, 2010).

Positive Monitoring (Porterfield, 1987) is another relevant system to measure the accuracy and effectiveness of staff performance. It was designed for services for people with intellectual disabilities and was integral to pioneering, successful community-based service initiatives around 30 years ago (Lowe and de Paiva, 1991). Like PSR, Positive Monitoring also focuses on service improvement by paying attention to staff performance, the provision of positive and constructive feedback, with additional targeted training to support improved performance when necessary. Unlike PSR, positive monitoring is conducted through direct observation of staff performance, providing another key tool for practice leaders for maintaining standards over the long term once initial competence has been achieved. It has five key components: defining service aims and outcomes for service users; specifying clearly what staff should do to achieve these aims; helping staff to work in specified ways; regularly observing staff working; providing specific feedback to individual staff members, and reviewing individual job performance. It's key characteristic, however, is that it is based on positive behavioural principles, in that the main focus is on reinforcing what staff have done correctly, an aspect usually ignored in traditional management practice. Done correctly, positive monitoring turns management supervision into a supportive rather than punitive experience.

There has also been a growing recognition of the need to professionalise the health and social care workforce by formal registration and compulsory qualification. The latest development in Wales is that all support workers must register with the lead organisation, Social Care Wales, within six months of their employment (Care Inspectorate Wales, 2022), with registration dependent on them either holding or working towards specified qualifications. The qualifications framework has been updated several times to address the increasingly recognised need for specialised knowledge and practical skills for both health and social care staff (Social Care Wales, 2022). However, rates of pay continue to present dilemmas. Support workers are still amongst the lowest paid, often earning considerably less than staff in supermarkets who require no qualifications. This means that a lot is being demanded from direct care staff for minimal financial reward. This is a major current issue as it devalues the work and results in high staff turnover and recruitment difficulties, with many services dependent on temporary agency staff who have little relevant experience and no knowledge of the people being supported, representing a major threat to service quality (The Guardian, 2023).



5. Legislation, guidance, and funding

The changes in service direction and delivery have occurred against a backdrop of government legislation that continues to be changed and refined. In addition to some key historical government papers mentioned earlier, other significant ones include the **Mental Health Act 1983**, the **Disability Discrimination Act, 2005**, the **Mental Capacity Act, 2005** which incorporates Deprivation of Liberty Safeguards, all of which were introduced to help emphasise and protect the rights and dignity of the individual.

The Winterbourne scandal of 2011 (Bubb, 2014; 2016) gave rise to a plethora of new government guidance across the UK (DOH, 2012) and, in Wales, culminated in legislation via the **Social Services and Well-being (Wales) Act 2014** (Welsh Government, 2014) which is still the major influence on service provision. This requires significant changes to the way social services are planned, commissioned and delivered to all client groups, characterised by a stronger emphasis on increased citizen engagement, prevention and early intervention, the promotion of well-being, co-production and multi-agency working and co-operation.

The core principle of the Act is the focus on well-being of the person who needs support and carers who need support. This encompasses physical and mental health; emotional well-being; protection from abuse and neglect; education, training and recreation; domestic, family and personal relationships; being able to participate and contribute to society; respecting and securing rights and entitlements; achieving social and economic well-being, having suitable living accommodation, control over day-to-day life and participating in work. It requires all those responsible for service delivery, including Welsh Ministers, local authorities, local health boards and other statutory agencies, to promote the well-being of people who need care and support, and of carers who need support, and to empower them to contribute to achieving their own well-being.

Another key initiative in Wales is the **Learning Disability Improving Lives Programme** (Welsh Government, 2018), which provides a series of detailed recommendations with three key priorities. The first is to reduce health inequalities through reasonable adjustments to mainstream services and access to specialist services when needed. The second is to improve community integration, including increasing ordinary housing options closer to home, integrated social care, health and education, and increased employment and skills opportunities. The third priority is to enable improved strategic and operational planning and access to services through streamlined funding, better data collection, partnership working and more training and awareness. This initiative was delayed due to the COVID-19 pandemic and then re-launched as the Learning Disability Delivery and Implementation Plan 2022 to 2026 (Welsh Government, 2022c) to promote PBS, trauma informed care, co-production and collaboration, and reduce restrictive practices.

Funding must be acknowledged as a major contributor to the development of community-based housing services. While additional government monies have been made available at times to promote different stages of service reformation, ongoing costs have been met through the established welfare benefits system operative throughout the UK and through '**Supporting Living**' funding which is specifically aimed at enabling vulnerable



groups of people, including people with intellectual disabilities, to live more independently and avoid institutional care (NDTi, 2010).

Supported Living is more cost effective, as capital costs of developing ordinary housing via registered social landlords can be funded by capital grant from Welsh Government and income from housing welfare benefits that pay rents. This is in stark contrast to residential care where capital costs are met by the local authority with no other grant funding available. Supported Living is also more advantageous to the people being supported as they have security of tenure, the right to choose who supports them and who they live with, and rights to full welfare benefits. In contrast, people in residential care have no security of tenure, no choice in who they live with and very limited funds at their disposal.

The Welsh Government recently introduced an integrated health and social care regional revenue fund to deliver a 5-year programme of change from 2022. Key aims are to promote: community-based care with a focus on preventative working, community co-ordination and providing complex care closer to home; good emotional health and well-being; supporting families to stay together; home from hospital services, and community-based accommodation solutions (Welsh Government, 2022a). To support this revenue funding, the Welsh Government also introduced a programme of capital funding that focuses on integrating health and social care, eliminating profit from the provision of care by working with not-for-profit providers to expand local community-based provision. The vision is that these initiatives will consolidate the longstanding policy in Wales of small-scale community-based, ordinary housing for all people with intellectual disabilities (Welsh Government, 2022b). This is markedly different from funding in England, where the way in which the healthcare economy has been encouraged to develop by recent governments has turned people with intellectual disabilities and challenging behaviour into commodities that are often exported to privately run hospitals, where they become a source of millions of pounds of income and profit (Brown et al, 2017).

6. Co-production

Co-production is one of the main principles of the Social Services and Well-Being Act in Wales. Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and that engages groups of people at the earliest stages of service design, development and evaluation. It acknowledges that people with 'lived experience' are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective.

Actively involving people and their carers in the design and delivery of the support they receive has been on the agenda for many years in Wales. The Welsh Government has provided funding to self-advocacy and family carer groups and included them as equal partners on government advisory bodies and so they have played an active role in shaping national policy and guidance. However, co-production at an individual and local level is still in relatively early stages. The impression is that younger families are now expressing higher expectations in this regard and their experiences in accessing direct



payments has enhanced their desire for more active involvement in the co-design and co-delivery of their support packages. The third sector is often considered to be the most advanced in these approaches but there is still some way to go.

7. Concluding remarks

Something that has not changed with deinstitutionalisation is that most people with intellectual disabilities continue to live in their family homes, as they have always done.

Prior to the 1980s, the majority of those not in family homes lived in large-scale specialist learning disability hospitals and hostels. Forty years on, no large-scale settings for people with intellectual disabilities remain and, within the community-based services, there has also been a major shift towards supported living in preference to residential care.

The overarching view in Wales now is that deinstitutionalisation has been achieved and that it has been a beneficial movement. The research agenda has moved away from investigating the benefits of community-based versus hospital care, and examining the general quality of community services, focusing now more on specific elements of practice such as Active Support, PBS, and restraint reduction.

However, a key lesson is that there is no room for complacency. Although deinstitutionalisation is no longer debated, there is still a danger that the worst aspects of institutional practice re-emerge, as scandals in recent years have demonstrated repeatedly. If the root causes leading to these scandals are not addressed effectively, complacency or acceptance of poor standards could easily lead to a re-introduction of institutional-styled provision.

It can often feel frustrating that things do not change quickly enough. However, on reflecting over the last four decades, it becomes clear that true change necessarily takes a long time to achieve. It requires not just changes in funding, legislation, services structures, training for staff and so on, but also changes in cultural expectations, and this is likely to need a generation or two to evolve. So, to keep the impetus for change alive and high on the agenda, it's also important to celebrate successes and mark significant milestones to help keep track of how much progress has happened.



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