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**United Nations Convention on the Rights of Disabled People – England Civil Society Shadow report – Changing Perspectives and Free Our People Now submission focused on people with learning difficulties & Autistic people in psychiatric settings December 2021**

**Changing Perspectives**

Changing Perspectives has 25 years' experience of championing and campaigning for disabled peoples' human and civil rights working at a grass roots and national level. Since the last UNCRPD Monitoring Committee’s report on the Government’s progression on the implementation of UNCRPD, Changing Perspectives main area of campaign work has focused on inclusive education, deinstitutionalisation and bioethics. For more information see Changing Perspectives website: www.simoneaspis.co.uk

**Free Our People Now Campaign**

Changing Perspectives set up the Free Our People Now Campaign in response to people with learning difficulties and autistic people not leading the deinstitutionalisation campaigns and to provide peer support for inpatients without family members. Inpatients have asked me to be a peer advocate because statutory independent mental health advocacy services (IMHA) are funded and arranged by the hospital and as such are not truly independent from the institution.

For more information see <https://www.simoneaspis.co.uk/index.php/advocacy>

**Statistics**

**The** NHS figures for 2021 report a 10% rise in patients admitted to psychiatric hospitals compared with six years ago in 2015. Themajority of detentions are made under the Mental Health Act 1983, despite autism and learning disabilities /learning difficulties are not mental disorders. The average hospital stay is five years. However, 100 inpatients have been held in hospital detention for more than 20 years in ‘institutions.

The Children’s Commissioner reported numbers of children with autism and learning disabilities/learning difficulties identified in mental health hospitals is raising steadily. 250 children with a learning disability or autism were identified in a mental health hospital in England in February 2019, compared to 110 in March 2015. Children are being detained in hospital for too long. Once detained under the mental Health Act It’s very difficult to be discharged from hospital. NHS Digital reports that on average, children with autism and/or a learning disability had spent 6 months (184 days) living in their current hospital, and 8 months (240 days) in inpatient care in total. Around 1 in 7 children had spent at least a year in their current hospital spell with their current provider.

The conditions in these mental health institutions have not changed since Panorama’s exposure of Winterbourne View Hospital scandal first broadcasted during 2011. People with learning difficulties and Autistic People are still routinely being abused, treated inhumanity and dying in state-sanctioned institutions. Over the past 5 years, there have been reports after report all affirming that psychiatric hospitals subject inpatients to brutal and inhumane treatment that the Government refuses to address by mandating a programme involves moving everyone out of such institutions into the community with the ultimate goal of ending institutionalisation of disabled people.

**Mental Health Act 1983 and Mental Health Act 2007**

The Mental Health Act 1983 is the main piece of legislation that covers the assessment, treatment and rights of people with a mental health disorder.

**Mental Capacity Act 2005 and Mental Capacity (Amendment) Act 2019**

The Mental Capacity Act 2005 is the main piece of legislation that covers the decision making arrangements for people lacking capacity.

***Have things got better, worse, or stayed the same since the last examination in 2017?***

Changing Perspectives and Free Our People Now can only report on the further regression and violation of disabled people’s rights to independent living and liberty, free from torture, inhumane and degrading treatment within psychiatric institutional settings since the publication of UNCRPD Monitoring Committee’s report on the Government’s progress in implementing UNCRPD Articles 19, 12, 15 and 14.

The Government’s Transforming care programme is meant to be an action plan focused on improving health and care services so that more people with a learning disability and/or autistic people can live in the community, with the right support, and close to home. The Transforming Care Programme’s aim is to have fewer people needing to go into hospital for their care. During 2020, the Equality and Human Rights Commission have sent a pre legal action letter to the Secretary of State for Health and Social Care, arguing that the Department of Health and Social Care (DHSC) has breached the European Convention of Human Rights (ECHR) for failing to meet the targets set in the Transforming Careprogram and Building the Right Support program. These targets included moving patients from inappropriate inpatient care to community-based settings, and reducing the reliance on inpatient care for people with learning disabilities and autism. Following discussions with the DHSC and NHS England, Equality and Human Rights Commission (EHRC) were not satisfied that new deadlines set in the NHS Long Term Plan and Planning Guidancewill be met. This suggests a systemic failure to protect the right to a private and family life, and right to live free from inhuman or degrading treatment or punishment.

There has been no genuine attempt by the Government to work with Changing Perspectives and Free Our People Now campaign or other disabled people’s lead organisations to develop a national independent living service including a deinstitutionalisation plan as set out in the UNCRPD committee’s concluding observations and recommendations. On the contrary, the Government’s decision-making processes and policies are being geared towards the increasing segregation and institutionalisation of disabled people.

**The Government has failed to address the observations and implement recommendations supporting disabled people’s rights to equal recognition before the law as set out in UNCRPD Article 12.**

The Government has failed to address the UNCRPD’s Monitoring Committee’s concerns over the UK’s legislation, Mental Capacity and Mental Health Act provisions restricting disabled peoples legal capacity on the basis of actual or perceived impairments. There has been no further advancement in incorporating supported decision making arrangements for disabled people lacking capacity and mental health conditions within UK legislation. There has been further regression in Mental Health and Capacity law.

The Mental Capacity (Amendment) Act replaced the existing Deprivation of Liberties (DOLs) with the Liberty Protection Safeguards (LPSs), the legal framework governing care and treatment decision making arrangements for people lacking capacity. The Mental Capacity (Amendment) Act enacted in 2019 has weaken legal safeguards for people lacking capacity. The LPS will now cover hospital or care home and anyone being cared for in any domestic setting, such as supported living, shared lives schemes, or even within their own homes. Care commissioners, funders and providers will be placed under the duty to conduct LPS assessments, authorisations and renewals covering person’s capacity, mental disorder and deprivation of liberty justification. No longer will LPS decision makers are required to consider the disabled person’s best interests. Changing Perspectives have no confidence in the system that allows a conflict of interest, where the Care Commissioners, funders and providers involved in the LPS authorisation process whilst being in receipt of financial arrangements. Disabled people lacking capacity and their advocates who want to challenge LPS decisions must use expensive court of protection arrangements on a very limited income means. The Mental Capacity (Amendment) Act does not include the state’s duty to promote disabled person’s liberty which is incompatible with promoting their UNCRPD rights. The draft LPS regulations and Mental Capacity (Amendment) Act consultation was meant to be published during summer 2020, now has been delayed until 2022.

**The Government has failed to address the observations and implement recommendations that will support disabled peoples’ rights to liberty and security of the person as set out in UNCRPD Article 14.**

There has been no genuine progress to repeal the Mental Health and Mental Capacity Act provisions allowing detaining and compulsory treating of people with learning difficulties, autistic people and those with mental health conditions. Whilst the Government has published proposed reforms to the Mental Health and Mental Capacity legislation. detaining of disabled people will still continue. Whilst the proposals include removing the provisions for detaining people with learning difficulties and autism from the civil sections of the law, nevertheless compulsory detention will still remain in place for those who would otherwise be convicted of a criminal offence. Whilst, the proposals may appear to be progressive, our concern is that the same group of people will find themselves being funnelled through the criminal justice route. .

The Crown Prosecution Service guidance for suspects with mental health conditions focus on the criminal trial itself without consideration the criminal offences definitions themselves. There appears to be no research examining whether legal criminal offences definitions interpreted by lawyers, judges and juries would unintentionally include disabled peoples impairment-related behaviour. The legislative proposals will continue to violate disabled peoples’ rights to liberty.

**The Government has failed to address the observations and implement recommendations that will support disabled peoples’ rights to be free from torture and cruel, inhuman or degrading treatment or punishment as set out in UNCRPD Article 15.**

All the independent reports affirm that people with learning difficulties and autistic people detained in hospital are routinely subjected to chemical and physical restraint leading to inhuman and degrading treatment.

The Government have failed to amend Mental Health and Mental Capacity legislation to remove the state’s powers to both detain and subject disabled people to non-consensual medical treatments and chemical, and physical restraints.

**Whether any new issues have emerged since 2017?**

The ONS’s Coronavirus and the social impacts on disabled people in Great Britain report found that Disabled people more often indicated coronavirus had affected their life than non-disabled people in ways such as their health (35% for disabled people, compared with 12% for non-disabled people), access to healthcare for non-coronavirus related issues (40% compared with 19%), well-being (65% compared with 50%) and access to groceries, medication and essentials (27% compared with 12%)

Public Health England statistics found that people with learning difficulties are 6 times more likely to die from covid-19 than the general population. The statistics are even more shocking for young people with learning disabilities where they are 30 times more likely than other young people to die from covid-19. People with learning difficulties have been at higher risk of contracting and dying from covid-19 infections because they are more likely to be in shared accommodation including institutional settings such as hospitals. The Care Quality Commission regulator reported 106 recorded deaths in mental health hospitals between 1 March and 1 May 2020, compared with 51 over the same period in 2019. Fifty-four of these deaths are from confirmed or suspected coronavirus infections. CQC reported 490 recorded people with learning difficulties died while detained under the Mental Health Act in England between the start of March 2020 and the end of March 2021. 166 of those deaths were due to Covid-19, while 324 people reported to have died for "non-Covid" reasons. CQC investigation found many People with learning difficulties had “do not resuscitate” (DNR) orders included in their medical records during the second wave of the pandemic, in spite of widespread condemnation of the practice. GP surgeries had been found enacting DNR blanket policies for specific groups of people, in this case people with learning difficulties during the covid-19.

The Coronavirus Act 2020 gave the Government power to restrict and remove many of the rights we enjoyed in our every-day lives without recourse to Parliament. Disabled people experienced the brunt of the Coronavirus Act’s provisions where some of the most important legal rights were put aside or weaken under the disguise of keeping covid-19 infections under control and prevent NHS overload of patients with covid-19.

During covid-19 a number of legal actions were being pursed that affected people with learning difficulties and autistic people rights to independent living, access health and social care more generally throughout the covid-19 paramedic. Changing Perspectives supported various court cases challenging covid-19 regulations and policies that placed people with learning difficulties and autistic people at high risk of mental and physical health deterioration associated with deaths within institutional settings.

The National Institute for Health and Care Excellence (NICE) covid-19 critical care guidance stated that all adult COVID-19 patients should be assessed for “frailty” when admitted to hospital, and that “comorbidities and underlying health conditions” should be taken into account. [CFS “frailty” scoring system](https://static1.squarespace.com/static/5b5f1d4e9d5abb9699cb8a75/t/5dadc90bb11ecf3bce47f27e/1571670285023/Rockwood+CFS.jpg) consist of levels of frailty. Frailty score includes someone needing various help with day to day activities. Anyone with a Personal Assistants or anyone detained under the Mental Health Act would clearly be at disadvantaged when prioritising critical covid-19 life saving treatment. NICE revised and amended covid-19 critical care guidance after Hodge, Jones & Allen lawyers threated with judicial review proceedings on behalf of disabled people.

Changing Perspectives were surprised that the Joint Committee on Vaccination and Immunisation (JCVI) failed to recommend that people with learning difficulties are prioritized for covid-19 vaccinations. Both the JCVI and Secretary of State for Health and Social Care failed to take sufficient account of the evidence of the particular vulnerability of people with learning disabilities to Covid-19 if they are residing in institutional settings such as psychiatric hospitals. Changing Perspectives and People 1st Covid-19 Support and Action group worked with Bindmans legal team to mount a legal challenge to the Government’s covid-19 vaccination priority groups that did not include people with learning difficulties and autistic people without having to engage in judicial review proceedings.

Whilst the Government published the daily and weekly statistics of people dying from covid-19, they refused to give any break-down by groups with Equality Act Protected Characteristics, in this case people with learning difficulties and autistic people. Rook Irwin Sweeney who represented Changing Perspectives successfully secured the publication of the shocking statistics of people with learning difficulties and autistic peoples covid-19 deaths both in easy read and standard format without having to initial judicial review proceedings.

Disabled people experienced increased intersecting of disabilism, ableism and racism as a result of education, health and care covid-19 policies treating disabled peoples human rights with contempt. The Government has used the Coronavirus Act to weaken the disabled people’s Mental Health Act (1983) legal safeguards included:.

* 1 instead of 2 doctors are required to authorise a hospital detention
* Mental Health Review Tribunals held remotely as opposed to in-person, usually on the hospital grounds.
* No requirement to arrange a second independent doctor’s opinion to review the responsible clinician’s clinical treatment.

The Health Protection (Coronavirus) Regulations 2020 has had a real negative impact upon people with learning difficulties and autistic people who have or would be at risk of being detained under the MHA 1983. Over an 18 month period peer advocates have witnessed all sorts of adhoc rules and practices being put in place which frustrated inpatients maintaining some sort of emotional equilibrium and stability or improvement as articulated by one peer advocate:

*“My friend had been in hospital during covid-19 where he had experienced two locked downs. My friend had no visits with his mother who has been dying from cancer. Friend’s mother does not know how to use technology and therefore phone contact was only available. My friend was not allowed to go to the shops and had to wait until staff could do his shopping including buying sweets which he hated. During this time the staff cancelled all ward-based activities. Staff with full PPE in the office only doing essential tasks. Friend’s mental health deteriorated – he would shout and ‘kick off’ and was sent to his room to calm down. The hospital staff did not explain the covid-19 situation – it was left me to do it... My friend was only allowed to speak to me once a week between 3 to 4 pm.”*

**Total ban of in-person visits of any description**

Psychiatric hospitals banned on-site visits for everyone including occupational therapists, psychologists, independent advocates, CQC inspectors and tribunal doctors. Total visitors ban has had a dire impact upon inpatients health. Inpatients said they had nothing to do on the ward as in-person activities were suspended indefinitely including access to therapy sessions. Inpatients told me there increased incidents of bullying, assault, self-harming behaviour including starvation during long-periods of time being stuck on the ward. As I and others were not permitted onto the ward, it was difficult to ascertain what actually happened. The hospital can and have refuted against any suggestions that their inpatients were being subjected to any abuse, inhuman treatment and alike.

I reported the hospital to Local Authority’s safeguarding teams and CQC to investigate the inpatient’s physical state. The CQC were appalling - long waits on the phone whilst listening to The Beatles songs including Come Back. And unfortunately, that is what I had to do, come back too many times even on Christmas Day itself. To this day CQC had done nothing whilst the inpatient was starving in protest of community leave including home visits cancelled by hospital management.

Leigh Day lawyers represented 11 organisations (including Changing Perspectives) which support older people, people with learning disabilities, mental health support needs or autism have jointly written to the CQC to raise concerns about its decision to suspend inspections during the covid-19 pandemic. This is at a time where disabled people are most vulnerable to institutional abuse, isolation and wrong-doing.

Hospital frustrated any contact between inpatients and the outside world. Staff routinely even well into the covid-19 paramedic and locked down restrictions would tell me that they do not know where the technology is, how to set up the technology and no internet connection. Each ward had one computer clearly not enough when all face to –face contact had been suspended indefinitely by the hospital management. I was told on several occasions that inpatient could not have a 1-1 private meeting with me because there was other patient data on the computer. Absolute nonsense. I have a tablet that is set up without access to anything other internet search and social media platforms include skype and zoom and alike. The hospital clearly used technology to block any meaningful contact between inpatient and outside world.

A Mother sought a legal challenge against a psychiatric hospital for stopping contact visits with her child. She argued that the hospital failed to make Equality Act 2010 disability-related reasonable adjustments by allowing some kind of face-to-face contact visits to continue throughout covid-19 paramedic. The hospital failed to make any reasonable adjustments including facilitating virtual visits through providing on-line device so that the family are able to maintain some kind of face to face contact during covid-19 paramedic.

The Coronavirus Act and Health Protection (Coronavirus) Regulations 2020 included provisions which allowed people to leave their home for a reasonable excuse unless one is detained under the Mental Health Act 1983.

Single person households (did not include inpatients) could form a support bubble with another household consisting of one or more persons. This provision was added to the regulations so that single person households were able to have some social contact to combat the negative impact upon mental health. Disabled individuals residing in mental health hospital could not form a support bubble because they were disabled. Changing Perspectives explored options to challenge these regulations on disability discrimination and other human rights grounds. The patient had been discharged from MHA 1983 section and living in the community so this judicial review action had not been pursued by the legal team. A similar judicial review case begun to clarify whether disabled individuals in shared supported living accommodation can form a support bubble with another household. At the time, regulations had been amended to allow different households mixing without using support bubble provision.

Individuals in whatever form of accommodation could leave their accommodation to provide or receive personal care to maintain physical and emotional wellbeing. Respite care, family visits are included in the provision. Changing Perspectives believed family visits that took place prior covid-19 paramedic could had continued as per normal. Miles and Partners sent notice before judicial review including NG v Hertfordshire CC & others court case involving an autistic person with learning difficulty in receipt of 24-hour local authority funded care in their own home. The care provider wanted to stop family providing care because of the covid-19 locked-down rules. The judge upheld the disabled person’s right to receive physical and emotional support from their family members despite the locked down rules. Whilst Mills and Partners waited for a reply from the hospital, the inpatient was discharged from hospital into her own accommodation where the care provider facilitated her family visits.

In the UK, it has always been the case that public bodies are prohibited from having blanket policies in place and that the law and policy should ensure that decisions are made on merit about individual’s entitlements.

During the covid-19 paramedic, people who were detained under the Mental Health Act were subjected to blanket policies that meant they could not uptake the restricted freedoms that everyone had under the Health Protection (coronavirus) regulations. Even though hospitals were entrusted to balance the health risks of their staff, contractors and patients, nevertheless professional bodies recommended individual patient’s community leave (including home visits) should always be facilitated by the hospital with certain measures such as regular covid-19 testing being in placed. We heard from inpatients that community leave was suspended indefinitely despite professional bodies guidance making it clear that patients should still continue to use their community leave on the same terms as the rest of the population who were not detained under the Mental Health Act. Shopping, out-door exercise, attending medical appointments, visiting families and friends were some of the freedoms that the general population had during locked-down. Hospital management would have blanket policies that prohibited people detained under the Mental Health Act from up-taking the freedoms for everyone whilst on community leave.

Judicial reviews (JR) are the only legal method for challenging hospital blanket policies. JRs can only be initiated by lawyers by patients in receipt of legal aid and it can be a lengthily process. Independent advocates and other advocates have no power to legally challenge such policies. It’s for this reason why hospitals have got away with just having blanket policies that are most of the time are left unchallenged. So, there is no real effective way of challenging hospital blanket policies that are blatantly unlawful. Even when lawyers challenge hospital policies, the management soon backs down and will do the right thing, to consider each case on its merit so the case does not get heard by judges. So, in the majority of cases, people with learning difficulties and autistic people are continuous being subjected to unlawful practices whilst detained under the MHA 1983.

Even during covid-19 paramedic patients were still entitled to challenge hospital detentions using the Mental Health Review Tribunal (MHRT) procedures. An independent panel consisting of a lawyer, a mental health practitioner and qualified psychiatrist will decide to discharge a patient on hearing the evidence. Normally, such hearings are arranged face to face either in the hospital or alternative venue in the community. Patients are entitled to have legal representation for the MHRT hearing which they are able to attend in person. However, MHRTs moved on-line after the covid-19 paramedic begun and the Mental Health Act amended accordingly.

Some inpatients preferred in-person to remote MHRT hearings. The MHRT doctor’s perspectives have a profound impact on the panel’s decisions to discharge patients off hospital detentions. Without face to face encounters, the MHRT doctors have relied upon the heavily biased reports written by hospital staff. Even when doctors are able to talk to the patients, it will be restricted to phone calls and zoom meetings, both mediums do not provide the forum to pick up psychological subtle which can only be picked up by face-to-face contact. On occasions the tribunal doctor failed to undertake their own independent assessment what so ever. At least one NHS Trust sought legal clarification on the acceptability of remote examinations being carried out by doctors involved in making the decision around the sectioning process.

Devon Partnership NHS Trust in their court case against SSHC asked the judge to clarify the law clear regards to video examinations being permissible for making Mental Health Act hospital and Community Treatment Orders during covid-19 paramedic. The court upheld face to face examinations should take place between mental health professionals and persons being assessed for a hospital detention or Community Treatment order.

Patients were also very disadvantaged because they do not have in-person contact with their legal teams, advocates and other family members and peers. Unlike hospital lawyers working with hospital staff who would have their own private space, this is not the case for inpatients where the only permitted communication is done during the hearing itself unless breaks are scheduled with telephone calls. Also the quality of the hearings were very poor, often because of screen time, insufficient breaks, and a very poor internet connection and alike, all have a negative impact upon the inpatient’s mental health presentation. So, patients have experienced injustice where remote tribunal hearings proceedings will place patients with learning difficulties and autistic people at a substantial disadvantage.

***Which issues have had the biggest impacts on deaf and disabled people in England/most significant implications for the rights of deaf and disabled people in England?***

* The state only provides a duty to detain people in hospitals. There is no state duty to support disabled peoples’ rights to independent living including the assistance they require to thrive in the community as set out in UNCRPD Article 19 and ROFA’s National Independent Living Service.
* No deinstitutionalisation programme
* Mental Health and Mental Capacity laws that still allow the state to detain disabled people on the grounds of their disability. No longer depriving a disabled person’s liberty needs to be a best interest’s decision.
* No legislation that imposes a state duty to provide supported decision making arrangements

The Government is reviewing the Human Rights Act and Judicial Review Procedures with a view to weaken the state’s obligations to protect and uphold disabled people’s human rights as set out in international treaties such as ECHR and UNCRPD.

The Government wants to bring in legislation that would allow Ministers to override court judgments they have lost, be they passed by the European Court of Human Rights or British judges. This could have a significant negative impact for disabled people who may have won cases that support their rights to autonomy and control over their mental health treatment and care outside institutions. The Government could easily overturn decisions that would permit the increased segregation and institutionalisation of disabled people.

Disabled people’s civil right and human right to independent living and deinstitutionalisation would not have been achieved without years of active and sustained protests of all sorts, particularly around the Houses of Parliament and Government departments. The Government is bringing in legislation that will severely undermine our rights to protest within the Police, Crime, Sentencing, and Courts Bill. The proposals will allow the police significant leeway to stop our protests on grounds including noise and disruption to the public.

The Government’s plans to increase the state’s powers to detain disabled people in any form of accommodation involving non-consensus care and treatment will no doubt lead to – yet more – substantial attacks on disabled people’s human rights as set out in UNCRPD Articles 19, 12, 14 and 15.

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