Positive behavioural support in Norway: Context, values and aspirations for widespread systems of support

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Introduction

Norway is a small Nordic country with 5.3 million people known for its robust welfare system, high standard of living and strong focus on nature conservation and sustainability. Positive behavioural support (PBS) is becoming established as a framework for best practice in Norway to support quality of life for people with and without intellectual and developmental disabilities in the context of challenging behaviours and/or other areas of need. In short, PBS (or Positiv atferdsstøtte – PAS) is rapidly becoming considered a framework of support for all people. In this paper, we summarise aspirations and the development of PBS in Norway with a focus on core values and cultural context, intended beneficiaries, obstacles and solutions to implementation.

Establishing PBS in Norway

The situation in Norway today is that PBS is spreading at pace. This way of thinking and working is highly regarded by service recipients, parents, professionals and managers. Today we can observe various activities based on PBS knowledge, training courses and resources with PBS utilised across a range of settings.

Early ideas relating to PBS surfaced in Norway in 2006 in a book chapter by Gundersen and Moynahan (2006). It was not, however, until 2016 that ideas regarding PBS gained momentum through the leadership of Christine Spence (project manager), Eivind Mikkelsen, (senior adviser in Sandnes municipality) and Ulf Berge (academic, VID Specialized University, Stavanger). These three professionals coordinated their work between Jaattaa High School in Rogaland County, the municipality of Stavanger, and VID Specialized University in Stavanger. Together, they established a local PBS network and engaged the expert input of Nick Gore and Julie Beadle-Brown (University of Kent, UK) to guide the development of PBS through a series of trainings and consultations.

Samordningsrådet (SOR) is an important foundation in Norway that has also been very influential in supporting PBS. Its mission focuses on supporting persons with intellectual disabilities via information and professional/workforce development. SOR also provides social political input concerning attitudes and awareness of the challenges and developmental opportunities experienced by people with intellectual disabilities. SOR has now published seven thematic issues about PBS, which includes a translation of Gore et al.'s (2013) definition and scope for PBS, as published in the *International Journal of Positive Behavioural Support*. In 2023, SOR arranged the first ever two-day 'National Conference on PBS' to celebrate and further evolve PBS work across the country.

A further major influencer has been the Norwegian Directorate of Health, which works to strengthen the population's health and develop good health services by collating knowledge and experience and providing national standards in various areas. The Directorate of Health has been supportive of many PBS projects across

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Norway and has given many municipalities support for the implementation process. In 2022, the Directorate granted funding to the municipality of Sandefjord project to establish a national network for PBS. The steering group has representation from various health and care services, primary schools, pedagogical psychological services, academic institutions, SOR and the National Institute on Intellectual Disability and Community. The PBS Network is working to encourage a commitment to the principles and guidelines described in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD: United Nations General Assembly, 2006), which emphasise breaking down disabling barriers and securing equal rights across populations. The PBS Network will be an important vehicle for putting knowledge of implementation on the agenda, to stimulate the sharing of research close to practice and to encourage cooperation within and across PBS communities. It is an inclusive network and everyone is welcome. The PBS Network meets twice a year, once physically and once online.

Notably, the Directorate of Health has published new guidelines for good health and care services for persons with intellectual disabilities (Directorate of Health, 2021). The guidelines describe the requirements for services that will ensure a satisfactory service in a lifespan perspective. This holds an equivalent status to the National Institute for Health and Care Excellence guidelines in the UK. In the Directorate of Health guidelines, PBS is explicitly described as best practice due to its evidence-based approach, individual focus, preventive nature, ethical principles and documented effectiveness. It is recognised as respecting individual needs and rights, reducing behaviour that challenges and providing cost-effective results, which makes it a preferred approach in the care of people with various challenges. Finally, the Directorate of Health has also recently supported organisations coming together to produce an animation related to Gore et al.'s (2022) updated definition of PBS (https://youtu.be/ DpwgRDnT0Ag?si=18KaTCNmz6J3qSqX).

Contexts for using PBS in Norway

Norway has a long-standing commitment to deinstitutionalisation, and the majority of adults with intellectual disabilities in Norway live in community settings with equity in terms of rights. Every child with intellectual disabilities has the right to education and the trend is that all children will join in the same classroom in inclusive environments. There is a commitment to supported employment for people with intellectual

disabilities in Norway and support for access to a range of leisure and social activities. Services for people with intellectual disabilities are typically publicly funded as part of Norway's welfare state and organised according to an individual's needs and situation. All citizens have access to necessary services, regardless of economic status.

Today, the dominant perspective in leading public documents in Norway concerns a relational understanding of disability. This is a social model of disability that highlights the relationships between aspects of a person's condition and the suitability of the arrangement of their surroundings. The political signals in care policy in Norway, based on empirical claims and normative arguments (e.g., the Health and Care Services Act 2011; Meld. St. 6 (2019-2020); Meld. St. 10 (2012-2013); and Regulations of management and quality improvement in health and care services [Ministry of Health and Welfare, 2017]), have been that service recipients are entitled to a well-managed service and living environment. Services should be delivered according to individualised needs, where people have the right to and a duty to be active citizens, and to have a life devoid of the use of restrictive practices. One example is the legislative act related to equality and prohibition against discrimination (Prop. 81 L. [2016-2017]), which makes it illegal to discriminate against people with a disability in terms of education, work or society at large. In this context, Norwegian society is committed to accommodating all citizens. The municipalities have a duty to see to proper, well-arranged and individually adapted services, which ensures that the use of restraint is avoided as far as possible.

However, quality of life in Norway is generally high, but skewed. In a recent survey of the population of Norway, 16% of people reported a low quality of life. Within this group, people with reduced health and those with a disability were overly represented (Nes et al., 2021). Even though the idea of equal human rights for people with a disability is highly valued, research shows an almost consistent breach of the rights of disabled people in nearly every area of life, as documented by the Norwegian Ministry of Children and Equality (NOU, 2016, p.17), the Norwegian Board of Health Supervision (2017) and the office of the Parliamentary Ombud (2022).

There are several normative guidelines concerning **best practice** in Norway in the context of behaviours that challenge (e.g., Health and Care Services Act 2011 and Norwegian Directorate of Health, 2015). Overall, Norwegian guidelines describe strict and extensive demands on safe and effective services and high-quality

environments. Restrictive practices are always positioned as a last resort strategy. In Norway, there are four regulations regarding the use of coercion and force, one of which is specifically aimed at people with intellectual disabilities. A public committee recently recommended that all of these laws be merged into a common coercive limitation law for the Norwegian population (NOU, 2019, p.14). A common law provides a good opportunity for a uniform approach to human rights requirements.

Values that underlie PBS in Norway

In Norway, PBS is considered the pedagogy of everyday life that has a language, a values base, a scientific anchoring and an understanding that 'we are stronger together'. VID Specialized University and the PBS Network has chosen to closely collaborate with key partners from the UK in their approach to understanding PBS. Gore et al. (2013; 2022) defined core elements that make up PBS in the UK, and these are also our basis for defining and employing PBS in Norway. We refer primarily to the 12 core components in the updated 2022 UK definition as a framework for best practice, but have adapted the wording and emphasis of some components to better-fit Norwegian cultural contexts.

As such, the four values and rights components outlined by Gore et al. (2022) are maintained, but with slightly altered wording to the first and second components. In the first component, we refer to 'person-focused' rather than 'person-centred' foundations, since the latter is often used in other contexts in Norway and does not convey the central focus on an individual's life quality, priorities and needs in the same way as it is intended in the UK. The second core values component is worded as 'constructional approaches and self-determination' in the UK. In Norway, we word this as 'empowering, enabling and supporting practice'. The text accompanying the description of this component in the UK definition references empowerment, and this is particularly important for us to highlight.

We emphasise the importance of working to encourage a person's own capacities to meet life's challenges as an act of empowerment or self-power mobilisation. This is referred to as self-determination in the UK description. The concept relates to the use of power and the transfer of power and represents an acknowledgement that pervading practice is all too often paternalistic and oppressive. We highlight how PBS calls for a change in mindset, shifting from a medical-expert model, in which professional opinions hold more influence than the

person's own views, to a truly person-focused practice. Such an approach, through careful facilitation, enables people to gain greater control over the factors that affect their lives. People should never be given assistance or help that ties them to our solutions and answers. The aim is to help in such a way that they are free to find the road to their own solutions.

The third component, 'partnership working and support for key people', is considered particularly important because success depends on team effort. The fourth component concerns elimination of aversive and restrictive practices. This component has great resonance in the Norwegian social and political context, as previously described. In Norway, we have a shared understanding with the UK that PBS is a collaborative approach and a long-term commitment that involves all stakeholders, including those who receive support, their families, caregivers and leaders. Similarly, we also recognise that success is more likely to happen and be effective and sustainable when people work together and pool skills, expertise and perspectives towards common goals.

Who is PBS used to support in Norway?

PBS is typically used in Norway to support people with intellectual disabilities in the context of challenging behaviours. However, many professionals and other stakeholders in Norway consider PBS to be helpful for all people and they have an aspiration to use PBS to help people in a wide range of contexts. This means people of all abilities and ages, including children, adolescents and adults in a variety of settings. We consider that ultimately 'people are people' and the mechanisms and values brought together in PBS have universal application and benefit. PBS in Norway is therefore considered a framework for best practice, independent of diagnosis, challenge or age.

Similarly, many professionals and other stakeholders in Norway consider that PBS may be helpful in situations where behaviours that challenge are not the focus. The conceptual model that we have been developing, which underpins how we define and utilise PBS in Norway, concerns how biological, psychological and social variables influence health and wellbeing more broadly. It is important to emphasise that we also continue to see and use PBS as the central way of providing support for people with or without intellectual or developmental disabilities to reduce the risk and impact of behaviours that challenge through maximising quality of life.

Where is PBS used in Norway?

An increasing number of municipalities (currently 15% of all municipalities in Norway) and private care providers now adopt a PBS framework for their services across populations (i.e., for people with and without intellectual disabilities). One recent example of the expansion of PBS is the municipality of Alta in the north of Norway where the local authority has implemented PBS principles and structures as the framework across their services.

However, PBS in Norway is most commonly used in services for individuals with intellectual disabilities. This population often faces unique challenges with regard to communication, social interaction and everyday skills. People with intellectual disabilities rely more than others on the organisation and skills of services for their day-to-day life. Behaviours that challenge can significantly impact quality of life for people who display them and for those who support them. Several Norwegian studies (Saleem, 2019; Eilertsen, 2021; Enger, 2021; Sætrevik and Halvorsen, 2023) show that PBS has had a significant positive effect on the lives of people with intellectual disabilities who use services. For example, Saleem (2019) reported substantive reductions in behaviours that challenge following the use of a multi-element approach with a 65-year-old woman with a moderate developmental disability and history of aggression directed at staff. Elin Hansen has taken on a leadership role in advancing PBS within a large municipality, overseeing the care of 185 individuals with intellectual disabilities and coordinating with 330 service providers. She comments as follows:

"PBS has been a real change maker. If you get the environment right, if you listen to the people that use services, if you address the person's needs and preferences, then often you don't need more complex interventions. What we see is a change in attitude towards the focal person. The focus on building rapport and the low arousal approach has decreased coercive practice and injuries to employees. The everyday language and equality thinking, for example, about the tacit knowledge that the staff and family members holds has strengthened the partners. The professionals have better reflection and analysis skills, and a stronger professional 'backbone'. Assessments are supported to a greater extent by professional mapping tools. In our municipality we see that there has been a real culture change with better life quality and also that behavior that challenges has radically decreased." (Hansen, 2023, personal correspondence)

Several mainstream and special schools have also now implemented PBS. In most situations, tiered models of support have been utilised, but with changes to the typical school-wide PBS strategies employed. At Jaattaa School, this has included use of active support and other models of best practice as part of a school-wide strategy, following training and support from Gore and Beadle-Brown. Schools also have appointed special staff to function as practice leaders to keep the PBS process advancing. Finally, PBS and related ideas have now begun to be implemented in health service contexts in Norway.

Qualifications, training and accreditation of PBS in Norway

PBS has gained momentum in academic society in Norway over the past five years. It is now taught in tertiary vocational education courses and in Bachelor's and Master's programmes. The PBS continuing education programme at VID Specialized University includes Master's level. The programme is taught over a year and consists of seven gatherings, each lasting three days. This programme is now in its seventh year and is very popular. In 2023, 40 students enrolled and represented a variety of professional backgrounds, fields of practice and geographic affiliations. In 2018, the first graduate Master's thesis about PBS was written by a student at the University of Oslo (Hernes, 2019). Since then, several Bachelor's and Master's students have completed theses on this topic. Another PBS programme is an advanced vocational programme for professionals in which students must have a certificate of apprenticeship. The aim of this programme is to keep the training practical and demands 150 hours in the practical field related to the programme. There is, however, no formal requirements for accreditation of PBS in Norway. A major challenge, therefore, is that PBS practice can vary considerably from one service setting to the next.

Key barriers to PBS in Norway

In addition to unregulated training requirements, there are several other barriers that pose a threat to the practice of PBS in Norway. Most worrisome are municipalities that are experiencing economic difficulty and have begun to discuss and make decisions about returning to larger living units for people with a disability. The UNCRPD guidelines that insist that people be allowed to live where they want to live (e.g., see United Nations General Assembly, 2006, art. 19) are being put aside when economic arguments based on large-scale congregate living are presented. Neither the professional perspective nor the user perspective is listened to, even though both claim that it represents a crisis to move in a direction of increased

segregation and forced communal living. This represents a great challenge to giving adequate and professional services consistent with PBS in an environment that creates an increased risk for the development and maintenance of behaviour that challenges. Organising services in a manner that excludes human rights and marks a return to institutionalisation is clearly not the way to go. Paterson (2011) speaks of cultures that have been corrupted and how they make organisations poisonous. Within these types of environments and cultures, it becomes incredibly challenging for staff to operate in ways that reflect the values and strategies of PBS.

The future of PBS in Norway

In Norway, the aspiration for PBS is a framework for everyone, based on the UNCRPD which claims that disability arises from the interaction between an individual's particular needs and the attitudes, environments and barriers created by society. PBS represents an integration of rights and contemporary values and a pragmatic behavioural analysis of how learning and behavioural change can best take place. PBS, as it develops in person-focused ways, should retain the discipline of collecting robust data, consistent with its underpinning scientific basis. This will be an important direction for further development of PBS in Norway.

The challenge to implementing PBS in Norway has been and will continue to be finding an acceptable and effective balance between the objectivity and rigour of the experimental methods by which PBS interventions and supports have been and continue to be developed, and the pragmatics and flexibility necessary to adopt and adapt these interventions and supports in applied settings. More research is needed concerning the key components of PBS and how acceptable, effective, efficient and sustainable these are in practice. It may be that PBS (and the expanding use of PBS in different contexts within Norway) has created opportunities in areas not traditionally studied within behavioural analysis. Building an evidence base in new areas of practice may lead to an extension of concepts, methods and empiricism that is in line with but further builds upon the visions of the visionary pioneers of PBS (see Horner et al., 1990; Carr et al., 2002).

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