Review and Recommendations for the An Saol Service

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Introduction

This report provides recommendations from the NCPPD for strengthening the current service provision from An Saol and for the development of similar services regionally. It synthesizes reviews provided by three independent experts who were commissioned by the NCPPD, to provide opinions from their respective backgrounds in physiotherapy, rehabilitation medicine, and clinical neuropsychology. These reports were provided by (in alphabetical order) Fergus Gracey (BSc, MSc. ClinPsychD. Dip PG C.Psychol.) Clinical Associate Professor and Consultant Clinical Neuropsychologist, Dept Clinical Psychology, University of East Anglia; Anthony Ward, (MBE, BSc, MD, FRCP) Professor of Rehabilitation Medicine and Consultant in Rehabilitation Medicine; and Laura Wheatley-Smith (BSc, MSCP, MLACP), Principal Physiotherapist at Belfast Health and Social Care Trust.

NCPPD's "ask" to reviewers was to provide a clinical evaluation of the service provided by the An Saol Foundation. Specifically they were asked to assess the clinical effectiveness, impact and robustness of the Model of Service which An Saol provides from a holistic perspective using a BioPsychoSocial conceptual lens. Reviewers were provided with An Saol documentation, HSE policy documents; they visited the service, meeting clients, staff and board members, as well as HSE staff including regional and national leadership, the

NCPPD clinical lead and programme manager. Following a collective discussion, reviewers wrote their own independent reports.

This report does not replace the individual reports of the reviewers, which are appreciative and constructive commentaries on the An Saol service, and which should be read in their own right (they are reproduced in full as annexes to this report, Appendix 1 – Fergus Gracey, Appendix 2 – Anthony Ward, Appendix 3 – Laura Wheatley Smith). The reviewer's and the CEO of An Saol have been given the opportunity to make factual corrections to this report and these have been incorporated. An Saol have also made helpful clarifications to the reports of the expert reviewers, and these are available in a separate document.

This synthesis report provides twelve recommendations from the NCPPD for the future of An Saol and related services (these are listed on pages 13-15).

An Saol Model of Service

An Soal was established to provide services to people with a severe acquired brain injury (sABI) who did not have access to similar services within the state. While elements of the An Saol service may be found in services from other providers, the core element of An Soal's service provision are not available elsewhere. The model has evolved from that described in the original pilot proposal which was undertaken during the onset of Covid-19 and has had to adapt to unprecedented circumstances.

The core function of the service should focus on being a day-service for people with sABI, as this addresses an important gap in the provision of required services. An Saol does this in an innovative way and through an ethos which supports the realization of rights and helping people physically, socially and psychologically to function as well as possible. The service is best conceptualised as a Health, Wellbeing and Habilitation Service for people with significant needs arising from a severe acquired brain injury.

Article 26 of the United Nations Convention on the Rights of People with Disability (UNCRPD) is entitled "Habilitation and rehabilitation". Countries that have ratified the convention (Ireland ratified it in 2018) are required to provide a report to the CRPD Committee outlining their progress. The Irish state in response to this committee has used the following definitions of habilitation and rehabilitation:

“habilitation … is any service or support aimed at helping persons with disabilities to attain, keep or improve skills and functioning for daily living. It can incorporate Assistive Technology, therapeutic supports, or other health and social care support, as well as additional supports beyond the health and social care arena, such as services to support participation in education or employment.”

“Rehabilitation refers to regaining skills, abilities, or knowledge that may have been lost or compromised as a result of acquiring a disability or due to a change in one’s disability or circumstances. It can encompass the services and supports identified above.”

Habilitation therefore recognises that activities which improve health and wellbeing, including the realization of rights, are intrinsically valuable, even when they are not associated with a regaining of previously lost skills or functions. However, it may also be important for some to not discount the possibility that certain activities may hold open the potential to benefit from future innovations in rehabilitation. People with sABI have health risks associated with deterioration in physical health (these may include but not limited to general health and wellbeing, bone health, digestive and bowel health, muscle weakness, contractures). Such conditions may result from neglect, lack of opportunity and/or negative attitudes from carers or clinicians.

Albrecht and Devlieger (1999) described the “disability paradox” where despite the negative attitudes of others (including clinicians) people with disability often experience a good quality of life. In the context of the lack of services for people with severe brain injury in the USA, Ezer et al (2020) note that this “violates their fundamental rights to human dignity, life, health, benefit from scientific progress, education, freedom of expression, community, marriage and family, and equality’. Similarly, Megan et al, 2020, discussing services for persons with disorders of consciousness, note that: “Because the prevailing medical and cultural view is that the injured brain cannot recover and regain lost functionality, resources for care thus fall off after acute survival is assured, and the marginalization of persons with a DOC begins. “ (p 269). These statements support Giacino et al’s (2014) view regarding disorders of consciousness (DOC) arising from brain injury, that “A paradigm shift should change the pervasive nihilism that continues to complicate patient management, family adjustment, medicolegal issues and healthcare policy in relation to DOC”. Finally, Young et al’s (2021) review of the neuroethics of disorders of consciousness highlights “a failure to understand how the prudential values or capacities for experience may change with disability”. In other words, what makes someone’s life a little better and how they experience that, may change as a result of acquiring a disability. Other people’s assumptions about what are valid ways of making life better, may however block people with disabilities from trying new ways to improve their life.

The An Saol service is addressing an important need in a valuable way which resonates with concerns expressed in the international literature. Neither the NCPPD nor our external reviewers are aware of a directly comparable service elsewhere. This innovative approach to service provision should continue to be supported and expanded. A number of issues should be addressed to strengthen the service and embed it in existing service pathways for people with disabilities in Ireland.

Policy Alignment

The work of An Saol is consistent with a number of national policies, Transforming Lives, the overarching policy for adult disability services and New Directions which addresses disability day services. New Directions places emphasis on the values of person-centredness, community inclusion, active citizenship and service quality. It is also consistent with the national health policy *Slaintecare*, through the provision of services in the community and promoting community living. It is aligned with the national health and wellbeing strategy *Stronger Together: The HSE Mental Health Promotion Plan,* in recognising the importance of a mental health component across all service provided or supported by the HSE. The An Saol service can also complement the *National Neurorehabilitation Strategy* through establishing links with the new community neurorehabilitation teams currenlty being established.

The values espoused by the An Saol service represents an important advancement in service provision aligned with the UNCRPD, with the European Disability Strategy, with the World Report on Disability (WHO, 2011) and with the Global Report on Assistive Technology (WHO/Unicef, 2022). The work of An Saol will contribute to addressing a priority in the HSE in terms of reducing the inappropriate placement of people under 65 in older persons nursing homes, as has been highlighted by the Ombudsman.

As noted already it is the insistence on a strong rights-based approach that is a unique and welcome feature of the An Saol approach in the context of sABI services. This also aligns well the Assisted Decision Making (Capacity) Act 2015 (ADMA), and the National Disability Inclusion Strategy. One of our reviewers also noted that the service addresses the need for **"**meeting basic human rights, hope for potential future gains in functioning, even if small, and prevention of decline and poor health that arises from neglectful care". This very much chimes with the ethos of 'not leaving anyone behind', an issue powerfully addressed in the Ombudsman's report entitled "Wasted Lives".

An Saol has committed to aligning with the nine key principles of the Interim Standards for Services and Supports for Adults with Disabilities:

1.Provide person-centred services and supports that are tailored to individual need
2.Provide person-centred services and supports that promote community inclusion and active citizenship
3.Provide person-centred services and supports that promote independence and a good quality of life for people using them
4.Promote and uphold the equal rights of adults with disabilities
5.Promote and improve the health and development of each person
6.Provide safe services and supports that promote positive risk management
7.Provide effective governance arrangements with clear leadership, management and lines of accountability
8.Plan and use resources effectively
9.Deliver responsive and consistent services based on evidence and good practice"

Key Elements of Continuing Service

The key elements of the An Saol service have evolved to be:

1. Promoting human rights - facilitating engagement in *meaningful activity* (leisure, physical fitness, socialising), seasonal celebrations and rituals, connection with others and positive emotions.
2. Promoting health and wellness – addressing health risks sometimes associated with inadequate support or "years of neglect in a nursing home" , such as general health and wellbeing, bone health, bowel health, muscle weakness, and contractures.

3. Promoting habilitation - providing activities and assistive technologies that give an opportunity for clients to improved function, even if minimal, relating to physical functioning and health, communication and capacity to interact with others, and opportunities for positive emotional states such as enjoyment and sense of achievement.
4. Promoting family support - providing opportunities for family members to gain support for themselves, information about their family member's condition, advocacy through formal channels, and informal social connections providing emotional and practical support; allowing them to be both more effective caregivers and better able to cope with the associated challenges of that role.

In order to achieve maximum potential for the clients and for service evaluation, these four domains of activities need to be provided by skilled staff, using an interdisciplinary approach, incorporating family members and clients, using detailed clinical assessment and monitoring, which incorporates structured programmes of support, with both individualised and standardised methods of monitoring progress and evaluating outcomes.

One of the reviewer's commented that in relation people's motivation to seek coherence of experience and of their identity, the holistic day programme, of An Saol provides "a good deal of conceptual convergence, which sets the approach apart from traditional neurorehabilitation models of provision" (the features of this are usefully tabulated in the reviewer's report).

However, it is also important to highlight some concerns with the approach which provides components of day services, and specialist intensive neurorehabilitation services, which are currently predominantly neurophysiotherapy and physical activity / robotic assisted exercise. As the service is envisaged as life-long, its description as post-acute may be understood to imply a much shorter intervention period. Furthermore as there is little expectation of restoration of neurological function, reduction of care needs, or improvement in functional abilities, this does not reflect a need for specialist neurorehabilitation resources.

Providing continuous, specialist, life-long, services for people with sABI requires a different type of conceptualisation and this is much more consistent with the above mentioned

Health, Wellbeing and Habilitation service. One reviewer also highlighted potential risks - "including clients becoming therapy-dependent, longer-term issues with client compliance, engagement, benefit, family / carer burnout, and staff retention". This reviewer also highlighted safeguarding and advocacy concerns for those people with sABI and prolonged disorders of consciousness, as such clients do not have the consistent awareness, capacity, or cognition to make decisions about their own needs / care. In the NCPPD's view such concerns extend to any model of service for this client group. It should be noted that the services being introduced through the Assisted Decision Making (Capacity) Act 2015 (ADMA) may go some way to addressing some of these concerns.

It will also be important to manage the expectations of existing clients and their families, as a development of services across a greater number of clients may mean that existing clients do not continue to receive the same level of service, at least for some of the time.

In the midterm review supplementary document produced at the request of the NCPPD, An Saol state that "Our moral and ethical beliefs mandate us to offer our clients access to an environment that promotes their physical, mental, and spiritual well-being. While some clients are in a better position to accept this offer than others, we subscribe to the EU and UN declarations that such an offer is an essential part of everybody's human rights, no matter the level of their (dis-ability)." These views and the delivery of the service align with a number of UNCRPD Articles 5 (equality and non-discrimination), 8 (Awareness raising), 9 (accessibility), 14 (liberty and security), 17 (protecting the integrity of the person) 19 (health), 20 (mobility), 21 (express and access to information) 23 (family/home), 25 (health), 26 (habilitation and rehabilitation), 28 (social protection), 29 (participation) and 30 (culture – leisure – activity); reinforcing the rights-based approach adopted by the service. For instance, one client described the experience of using supported walking equipment as a feeling of 'being alive'.

While the effects of the use of this equipment for functional gain are unproven in this client group, it is important that gains not be narrowly conceptualised in terms only of the domains of function the intervention appears to be addressing, but also in broader and more personally salient terms for the person using the service. As noted by one of the reviewers a number of professional and standards bodies recommend exercise and activity for people with disability.

Indeed the Australian-based Bridges Project (2023) stands for "BRain Injury: Developing Guidelines for physical activities" and seeks identify the type of physical activity people living with moderate to severe traumatic brain injury should do. It is clear that a song case can be made for a human right to exercise (Messing et al, 2021) derived from a number of international human rights treaties, with associated state obligations. These ideas also chime with the ethos of the WHO (2021) guidelines on physical activity and sedentary behaviour.

Ireland has recently contributed to the development of a new WHO European Framework for the Highest Attainable Standards of Health for People with Disability, due pot be launched later in 2023. The motivation of this framework - "the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" – is to more fully implement the UNCPRD in the context of European Healthcare. The An Saol service represents a pioneering example of this ethos within the context of Irish health and disability services.

Staff Provision and Development

While the reviewers were very impressed and appreciative of the efforts of the An Saol staff, it is necessary to strengthen the staff provision and support their continuing professional development.

The drive and innovation of the An Saol CEO has been central to challenging the lack of services for this client group, and to championing the development of this innovative service. His family connection to the service has resulted in an exceptional degree of personal and professional investment of his time and commitment. He is supported by an Executive Council made up of several international and national experts in the field and a Board of five members.

The Clinical Lead for An Saol, a Senior Physiotherapist, brings considerable skills, energy and insight to her role and should be supported in developing this role further. A visit to An Saol in November 2022, by Dr Satish Misra, Head of Disability, Rehabilitation, Aging and Palliative Care, for the European Office of the World Health Organisation, resulted in an offer to connect the service and the Clinical Lead for the service with a new WHO

Collaborating Centre being established in Norway, and to support her to attend this Centre as part of her Continuing Professional Development (CPD). An Saol staff has received training and support from specialised centres in Germany that have also guided the standards of interventions.

The current team comprises the clinical lead physiotherapist, two additional physiotherapist, two rehabilitation assistants who have physiotherapy / OT qualification from other countries (but no CORU registration in Ireland as yet), a speech and language therapist, and a music therapist. A limitation to implementation of the An Saol model has been difficulty recruiting personnel, or securing clinical sessions, from other types of multidisciplinary team members. The NCPPD recommends that this would include, a senior full time OT, a weekly session form a senior clinical neuropsychologist, and from dietetics and social work.

For those clients attending An Saol the clinical team maintain links with medical specialists and GPs with regard to management of medications and routine specialist medical reviews with their relevant consultant /team. Links with the new Community Neurorehabilitaiton Teams should also be established. As noted below referral pathways, including with the National Rehabilitation Hospital, should also be clarified and strengthened.

Clinical Governance

As one reviewer noted “An Saol cuts across the current provision because it does not fit neatly in to a community rehabilitation facility model, nor into a day centre model” and that this is because the clientèle are a distinctive group and their needs are complex.

The New Directions document on Guidelines for EASI Process and Tools defines governance as “The function of determining the organisation’s direction, setting objectives and developing policy to guide the organisation in achieving its objectives and stated purpose. Effective governance arrangements recognise the interdependencies between corporate and clinical governance and integrate them to deliver safe and effective services and supports to people with disabilities.”

The alignment with national policy documents has already been noted above. Competency based clinical leadership, from a suitably qualified and experienced clinician from a relevant profession (health and social care professions, medicine, nursing) is also consistent with the approach of disability services. An important element of governance, particularly where recruitment of some professions is difficult, would be establishment of a Clinical Advisory Committee (CAC), drawn from non-An Saol staff, who are representatives of the disciplines involved in providing the service, service user representatives and other stakeholders, including the NCPPD. This CAC should meet every six months and receive updates from the CEO and Clinical Lead for An Soal, and provide guidance on service development, clinical standards and audit, clinical supervision, risk management, clinical research and continuing professional development. This structure would hopefully complement but be separate to the functions of the existing An Saol Executive Council, which brings a welcome range of non-clinical expertise to the governance of the organisation.

Service Pathway

To ensure equity of access to persons who may best benefit from the An Saol service, clear referrals pathways will need to be developed, including from the National Rehabilitation Hospital, from other service providers, from Community Neurorehabilitation Teams, and from civil society representative organisations; whilst also allowing for self/carer/family referrals, which has been a valuable aspect of the An Saol service.

These different pathways should be funnelled through a standard assessment protocol that assesses the potential for clients to benefit from the service that An Saol provides, and for those taken on by the service, to provide a baseline for future comparison. Regular assessments of health, wellbeing and habilitation should be undertaken, through both qualitative and quantitative means; sensitive to the possibility that very minor changes may have very positive benefits for some clients.

A clear pathway with the National Rehabilitation Hospital (NRH) should be established which would include the identification of need for continuing medical specialist support and review. Pathways to other service providers should also be clearly specified, and this should also include relevant trauma pathways.

Assessment, Monitoring and Outcomes

While a structured assessment process is in place it is not clear that routine outcome measures are incorporated into service planning. Triage and admission to service decisions for complex conditions should be completed by two or more specialist professionals to make the best decisions for potential service users.

One reviewer commented that they were “not aware from the review of routine use of formal assessment tools such as the CRS-R or WHIM to track subtle changes in behaviour that might indicate changes in consciousness, although the service does monitor client behaviour and responsiveness informally as a routine part of care.” The NCPPD has been informed that these tools are now in the process of being adopted by the An Saol service.

Behavioural changes should be reported in relation to goal attainment scaling, or some type of structured and systematic behavioural evaluation, including observational measure of mood state. Family members of clients may have significant needs and resources which might be assessed through positive measures as well as carer strain measures.

Specific suggestions for neuropsychological input include, structured and systematic evaluation of mood, formal assessment, psychoeducation and psychological support for family members, support for development of systems for evaluating individual change data and service evaluation, and neuropsychological assessment to include cognitive assessment and guidance on cognitive rehabilitation.

Review of data on assessment, monitoring and outcomes should be part of the remit of the proposed Clinical Advisory Group (see later).

Periodic Service Provision

While it is important that An Saol services should potentially be available to clients across their life-course, this does not mean that they should be continuously provided, or on a fulltime basis. To address the level of demand for the service (one reviewer estimates 25 people each year with sABI could fulfil acceptance criteria) it will be important to establish periods of more intensive attendance, of less intensive attendance and periods of no attendance. The duration of these periods should be related to the benefits clients are deriving and to the need for other clients to access the service.

It is important that the services of An Saol and other similar services that might be developed in other Regional Health Areas, be provided on an equitable basis. This would mean that all those who may benefit should get some level of service rather than a few getting an excellent service. It may also be the case that periods with reduced service, or no service, would allow for single-case monitoring and help to determine the optimal level of service which is likely to differ across clients. The intensity of interventions and the frequency of attendance should be varied based on evidence of benefit and need, and on the principles of equity and accessibility.

Attendance Facilitation and Equity

Currently, access to services is often physically facilitated by a carer or family member attending the service with the client, and also for the period of time the client attends the service. While this may be suitable to some family circumstances, it may not be possible for others and so could constitute a barrier to access. Alternative arrangements should be explored, costed and provided for, so as to make access as equitable as possible.

Exclusion from Service

The reviewers gained the impression that the primary exclusion criteria for acceptance into the An Saol service appeared to be displaying disruptive behaviour. However, it is understood by the NCPPD that some clients do display such behaviour (for instance, aggression or disinhibition) and that the need to strengthen staff training in this area is recognised by An Saol. In fact, individuals behaving in this way may be amongst those who have the greatest potential to benefit from the service. Such behaviour should not be a barrier to access, but rather the necessary services and supports should be provided to help the person manage their behaviour in a way that allows them to access the benefits of the service.

Strengthening Third Level Research and Training

The visit by the reviewers to An Soal provided an opportunity to meet with Prof Lizbeth Goodman. Lizbeth is Chair of Creative Technology Innovation and Professor of Inclusive Design for Education at University College Dublin, where she directs the Inclusive Design Research Centre of Ireland. Whilst Prof Goodman's team already contributes to An Saol this relationship could be further strengthened and research and implementation funding sought for new developments related to assistive technologies for people with sABI.

A letter of support was also provided to the NCPPD from Dr Tara Cusack, Associate Dean of Physiotherapy at the UCD School of Public Health, Physiotherapy and Sports Science, which indicated the value placed by the school on the student placements provided by An Saol. She also indicated the continued support of the School for the An Saol Service.

Given the existing links between An Saol and UCD, it would be worth exploring opportunities in disciplines such as psychology (where there are also some existing research links), social work, medicine, and nursing, for collaboration and student placements; along with speech and language therapy, and occupational therapy from other third level institutions.

An Saol should also identify existing expertise in assistive technology in other community or tertiary services to ensure that it is well networked and supported in developments in this area.

Recommendations

The An Soal pilot project has demonstrated the need for and value of providing a service for people with sABI, which supports their rights to health and wellbeing, facilitates their habilitation and supports the needs of family members who are usually key carers for and supporters of them.

The An Saol model of service is distinctive and innovative and does not have a direct parallel elsewhere. The model is best conceptualised as a Health, Wellbeing and Habilitation day service for people living with sABI in their community. This model should be strengthened and developed further allowing Irish disability services to play a leading role internationally in developing innovative day-services for people with sABI.

The focus of the service should be on people with sABI including clients with a prolonged disorder of consciousness, who are likely to require life-long support. Given the likelihood of demand exceeding capacity this will require clear criteria for acceptance / prioritisation, the likely provision of service for only two or three days a week per client, and periods of reduced or no direct service, but with continued monitoring.

The development services should include the following:

1. Existing staff contracts should be immediately extended to provide security of employment and maintain the existing standard of service and expertise.
2. Current approaches to assessment, acceptance, prioritisation, monitoring, and review of clients should be strengthened and made more systematic, whilst also continuing with the strongly individualized service provided.
3. Additional funding should be provided to enhance the service provision across additional disciplines as described above.
4. Stronger institutional links should be established building on existing third level links and An Saol should be established as a training placement for a range of different disciplines.
5. Links with centres of excellence in Germany and with a new WHO Collaborating Centre in Scandinavia should be formalised and each staff member should have a programme of Continuing Professional Development resourced.
6. A Clinical Advisory Committee should be established to support the clinical team and contribute to broader clinical governance, including ensuring alignment of the An Saol service with related pathways in the Irish health system. This committee should also review specific service improvements highlighted in the report of the expert reviewers and consider their adoption in the An Saol service.
7. With the transitioning to the new structure of six Regional Health Areas; each of these areas should provide a day-service to support the Health, Wellness and Habilitation of people with sABI, through an ethos similar to the An Soal service model. As the service grows it will be important to ensure a consistent approach, particularly with

the creation of new centres across Regional Health Areas. It will also be important to ensure that similar criteria are being applied to route people into these services and distinguish them from pathways that target active rehabilitation efforts in other services.

8. Funding for the developments above should be sought through the HSE Estimates process and be recurrent funding, and subject to ongoing monitoring and compliance with the standard suite of scheduled arrangements and agreements expected of any Section 39 organisation.
9. The HSE and An Saol should explore how it can partner and align with other organisations who also provide services for people with brain injuries so that An Soal can be part of a strengthened systemic approach to enhancing the lives of people with sABI.
10. With many developments across public health, mental health, primary care, disability, and older persons services, being driven by the Slaintecare policy, it is important that any new or continuing community day service have formal links to these other community services.
11. In line with the strong human rights ethos espoused by An Saol the service should also seek links with other community services, social prescribers, and voluntary groups; allowing An Saol clients to both potentially benefit from these activates and to raise awareness in the community of the service and clients.
12. A working group should be established to drive the management and systems related initiatives required to achieve the above developments.

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