ACQUIRED BRAIN INJURY IRELAND

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Submission

HSE Rehab Medicine Programme

Draft Model of Care

19 January 2015

National Clinical Programme Rehabilitation Medicine

Public Consultation on Model of Care from 24th November to the 17th December 2014
Comments to be received no later than 5:00 p.m. Monday 19th January 2015

Public Consultation Comments

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General		Effective policy development in relation to people with acquired brain injury (ABI) must be co-ordinated, seamless and comprehensive. Policy responses must be able to support the person in an holistic and individualised way, from the moment they acquire their injury to sustaining themselves in the community in the longer term. The current approach is entirely inadequate, fragmented and piecemeal. The proposed Rehab Medicine Model of Care (MoC) presented in this draft document is contributing to this fragmentation; it is continuing to prop up the piecemeal approach and failed policy-making process in relation to people with ABI. Although people with ABI and their families want to lead meaningful and fulfilling lives, the end result is that they are left merely to 'exist' after their injury. Comprehensive neuro-rehabilitation and ABI-specific services across the spectrum are essential to realising this goal, but the present policy-making process and the proposed MoC continues to fail people with ABI and their families.

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General		The draft MoC in its current form presents a number of challenges to those living with an ABI. Firstly, the model is entirely hospital based and exclusively medically and functionally focused. The rationale behind this has not been justified. It is acknowledged that people with ABI need medical care while they are in hospital (and in the community). However, these needs must be considered in an holistic and person-centered manner that involves the person and their family from the outset in all decision-making. The MoC fails to do this. In addition, the proposed solution to the majority of the issues and challenges to the system that are raised in the draft MoC is the provision of comprehensive community neuro-rehabilitation services. People with ABI, due simply to demographics, are the largest cohort of users of community neuro-rehabilitation. Therefore, these services need to have ABI-specific expertise. Community neuro-rehabilitation services are critical to the RMP realising its objectives (page 28) including reducing delayed discharges, length of stay in acute hospitals and specialist rehabilitation, reducing inappropriate discharge destinations and reducing readmission at EDs. ABI Ireland argues that the success of RMP in general and the MoC in particular, is predicated on the provision of effective and robust community based neuro-rehabilitation and other support services in the community. Therefore, it is extremely disappointing that the MoC *stops at the hospital door*.

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General (continuation from pervious section)		Such a system barrier (i.e., the failure to delineate the structure of services beyond the hospital) must be addressed, as must the custom of practicing in professional and disciplinary silos in an almost territorial way. Experience shows that this does not work for people with ABI. Their desire for a meaningful life, with community integration and participation, cannot be realised given the currently compartmentalised, ad hoc, under-resourced ABI services. A number of research studies have highlighted the importance of activities of daily living being practiced in natural and realistic environments in order to maximise new learning and enable relearning and the best place for this is within the person's own home environments. Within the Neuro-rehab Strategy the economic benefits of community based rehabilitation is also highlighted "*evidence suggests that these teams can provide models of care that surpass conventional hospital-based services in economic efficiency; also that they are as effective and achieve higher levels of patient satisfaction*", therefore specialist community services have as fundamental a role as specialist in-patient rehabilitation and this MoC needs to go well beyond its current arbitrarily defined parameters. ABI Ireland recognises the lack of leadership and ownership of the neuro-rehabilitation policy agenda within the HSE (and, by extension, the Department of Health). Leadership and ownership of the agenda by the HSE are essential first steps, in order to generate the type of policy responses that are needed. Only then will the MoC have any real meaning. It is very much appreciated that this is a complex issue, with HSE, in taking leadership, needing to work with multiple stakeholders, disciplines, sites and budgets. Within this, people with ABI and their families must be recognised as a key stakeholder in the process of policy and service development and be a core part of the decision-making. The MoC is developed on the basis that it will be embedded within a wide range of infrastructural developments and changes in the HSE. ABI Ireland is very concerned that a MoC will never be realised as a result of the lack of progress on key healthcare infrastructures in Ireland – PCTs, CHOs, hospital groups, as well as and the complete lack of investment in the necessary resources.

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	General	The language, tone and approach adopted in the MoC are excessively medical model focused. It is 'care', 'illness' and 'patients' that forms the core of the narrative throughout the document. The concept of the 'rehabilitation prescription' (page 18) is highly inappropriate. Neuro-rehab cannot be prescribed; it is tailor-made and highly individualised requiring interdisciplinary working. The duration, type and nature of the rehab process differs for every individual.
	General	The MoC take a very linear view of the rehab process for the person: acute injury-survival-hospital-go home. The reality of living with an ABI is that the process is not linear. People need support across their lifetime. Rehabilitation needs on-going management to make it sustainable and successful. The MoC must acknowledge these dynamics.
	9	Based on the description in the Executive Summary, there is no sense of how the MoC explicitly dovetails with the other clinical programmes referenced. While it references the Neuro-Rehab Strategy and mentions being "in line" with it, no real interface, which is vitally important for the journey of the individual, is promised.
	10	The Hub and Spoke model is simplistic but understandable if looking at a medical model only. Given that the expertise in the NRH is institutional and not community focused, and the model of care states that it describes the "generic and specialist competencies for staff working in rehabilitative care spanning acute, post-acute and community settings" perhaps a more streamed model would be more appropriate.

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	13/14	The Long Term Conditions Model is a well-established one. As presented in the text, "complex" is used to describe needs that are multi-factorial (i.e., one individual presenting with a combination of a number of physical, sensory, cognitive, behavioural, etc. difficulties). However, in practice, one factor (e.g. significant cognitive OR behavioural OR physical, etc. needs) may in fact cause huge complexity, requiring considerable specialist rehabilitation input. Any management model needs to be flexible enough to take this into account. For example, currently in order to access one HSE Community Rehabilitation Team, two factors of need must be evident; otherwise, the client is placed back with the Primary Care Team who does not have the expertise to deal with that client's specific rehabilitation need. The CRT must be person-centered and needs-based.
	16	It is very positive that the MoC references the International Classification of Functioning (ICF), as an application of the ICF paradigm in the Irish context will promote a more holistic, person-centered, and streamlined service structure. However, rather than describing the application of the ICF paradigm across all professional roles and rehabilitation levels (post-acute, regional, and community), the 'ICF and Specialist Rehabilitation' paragraphs describes this only within the medical/hospital context. The MoC also needs to include a focus on the biopsychosocial model.
	18	Other than the shared view of Managed Clinical Networks with the Neurology Programme, there is no sense of how the RMP would interface in a real way with other programmes with regard to the journey of the individual across the lifespan.

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	22	There is no mention of Towards 2016 or Healthy Ireland - A Framework for Improved Health and Wellbeing 2013-2025. Both of these documents have significant crossover with the RMP MoC and should be mentioned here. In addition, there is an international legislative context in the form of the United Nations Convention of the Rights of People with Disabilities, 2006. Article 26 refers to the rights to rehabilitation for people with disabilities and should be mentioned here.
	25	The reference to planning services only relates to those on the opposite ends of the spectrum (highly dependent patients and return to work for lower dependency). What about all those people with ABI in the middle of that spectrum who need support to regain function and reduce their dependency?
	27	The text states that "rehabilitation services within the community are often offered to patients with specific conditions rather than on the basis of need". ABI Ireland is very concerned with this statement. Across the board, neuro-rehabilitation services in Ireland are wholly inadequate. Those who have services, whatever the underlying condition, do so because they need them, and even then, these services are limited and inadequate. Very often services can only offer the bare minimum to prevent deterioration or homelessness, rather than the optimal level required to achieve functional independence. This statement in the MoC could be interpreted as suggesting that services are plentiful for some conditions, and that inequity in accessing services is due solely to the particular condition that an individual has; this is inaccurate and inappropriate. It should be replaced with a different sentence, potentially like: "Currently, access to specialist rehabilitation in the community is dependent on geography and the funding available locally to services". This refers to an aspiration that exists under Quality on p28 – "Ensure equitable access to specialist rehabilitation services regardless of geography".

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	27	The inadequacy of provision of essential aids, appliances and assistive technology was cited as hampering optimal independence within the Neuro-rehab Strategy and it highlights how *"Adaptations to housing, together with provision of appropriate aids and assistive devices, can be a cost-effective means of empowering individuals and providing enhanced quality of life",* yet housing/adaptations receives little to no mention in this proposed MoC. It states *"Lengthy delays in effecting necessary house adaptations and inadequate provision of essential aids, appliances and assistive technology present challenges to the effective provision of rehabilitation services. Solutions for these areas of need are outside of the scope of the RMP".* Why is this? Discharging people to suitable housing and carrying out adaptions to properties can be challenging and lengthy process. This can also be the cause of delayed discharges from in-patient services therefore, the housing and equipment needs further attention within the MoC. It is one of the core ways in which in-patient services become stagnated. Further investment and easier access to assistive technologies may lead to clients requiring less support services and a more a cost effective measure in the long term.
	28	Under the heading "Quality" the first bullet point refers to the reduction of inappropriate patient discharges to nursing homes. The RMP must also give consideration to individuals who are already living in nursing homes, in particular, whether they will have an opportunity for discharge to a more appropriate care setting, as per Quality point 2, and how will this be accounted for in the proposed MoC. For instance, many of those inappropriately placed in nursing homes are younger people whose rehabilitation needs are not being met in such environments. However, with neuro-rehabilitation and supports they could be discharged to live in the community. It would be useful if the MoC could reflect this possibility, and outline how this will be facilitated in the proposed model.
	32	ABI Ireland recommends that Rehabilitation Assistant is included in the description of the specialist rehabilitation teams as described in Table 2.

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	37	The NRH is identified as the national tertiary centre, with specific responsibilities related to education and training. While the NRH has considerable expertise in inpatient and outpatient rehabilitation, a number of other sources of expertise exist but have been overlooked. For instance, ABI Ireland, as a voluntary agency, has developed considerable expertise in the provision of community-based specialist rehabilitation services, and has a considerable amount to offer in relation to education and training (e.g., providing education and training to PCT staff or providing specialist placements for clinical psychology doctoral candidates and social care degree students). That fact that there is no recognition of this vast part of the continuum is of concern.
	36	The model identifies a number of key principles that should underpin infrastructural development. The first could be clarified further: – Be person- and carer-centered, responding to the individual's own priorities and needs at any given time.
	38	This section talks about the standards of in-patient and community rehab which requires a direct link with the Neuro-Rehabilitation Strategy but it is not referenced at all.
	40	It is very positive to see reference to case management. It needs a further element in that case management, to be effective, must be condition-specific.
	41	It is positive to see mention of the key worker role. In relation to self-management, thought is required in relation to how resources can be made available (bibliotherapy, online, etc.) to (particularly high-functioning) individuals in order that they can have greater control and autonomy over their own rehab plan. It will be helpful to outline how and where resources can be made available/accessed.

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	42	It is positive to see health promotion and prevention mentioned but it needs greater elaboration. What is meant by the reference on this page to "self-care"?
	45	ABI Ireland agrees strongly (as evidenced by international research) that effective rehabilitation can only be achieved with proper resourcing and that strategic, coherent evidence-based planning around capacity, needs and resourcing at appropriate levels of care is vital if people requiring services are to move in and out of the continuum seamlessly and without the system itself becoming blocked at different levels. In describing the service challenges, the narrative on this page is very negative in the way it frames current service provision as being "self-determined" by individual agencies and professionals in an "uncoordinated" fashion, leading to an "observed inequity" in provision across the country. This needs reframing to an alternative narrative to account for the fact that these agencies are operating services that are much needed, yet they are grossly underdeveloped and under-resourced. They are doing so in the absence of any meaningful policy planning/implementation from the state in relation to neuro-rehabilitation services in Ireland. The genesis of many of the services that currently exist was driven out of a dire need to respond to gaps in service provision, and a determination to address these gaps and deficits to support people to live meaningful lives. This is largely, though not exclusively, located within, the voluntary sector.

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	48	The MoC graphic is not clear; it is difficult to reconcile it with the person's journey as described in previous sections. It needs to be re-designed so that it can be clearly understood and followed by the reader as a stand-alone visual summary of the model. The family should be included where the "service user" is mentioned in the box on the left hand side, particularly given that there is a significant reliance on the family to provide support for family members with rehabilitation needs, and therefore the family is important in both providing and requiring support.
	49/50	In terms of assessment and recommendations, the process outlined is focused on new referrals entering the pathway in hospital settings (at regional and tertiary levels). However, a process must be outlined for individuals who enter the pathway in community settings. This is particularly necessary as there are many individuals living in the community with extant injuries/conditions, who have fallen through the current gaps in services; these individuals may require specialist rehabilitation, but are considerably past the point of diagnosis and acute assessment or intervention. It is not clear how individuals presenting to community teams can access rehabilitation consultants for assessment, if necessary (e.g., if a referral to a community team for an individual with a long-standing head injury has been triggered because of a significant recent change in behavioural or cognitive functioning).
	51	Details on service delivery, transfer of care, follow up and re-entry is too limited to have any real meaning for practical application. Individuals will likely be held in community services for a considerable period of time for rehabilitative input, and it is important that clear pathways of referral are outlined so that community-based clinicians can facilitate referrals for specialist review/assessment/intervention as needs may change over the lifespan of the individual. Furthermore, many community teams currently work without medical input, so it should be possible for allied health professionals to instigate referrals to secondary and tertiary centres, within appropriate limits (see also our comment regarding the lack of clarity in relation to how the RMP MoC interfaces with other national clinical programmes).

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	51	MCRN not linked to the Neuro-Rehabilitation Strategy in any way. Exclusively hospital based.
	57	The patient journey is described within the hospital, but importantly, is not described within the community-based specialist services element. The comments on the CRT are confined to referring to case manager, prosthetics and orthotics. Neuropsychologists and neuro-OTs are not included, and represent a significant omission, considering that these professions do not form part of the PCT make up. This omission is particularly unusual and significant given that on page 13 the MoC states that: "patients with complex needs typically present with a combination of medical, physical, sensory, cognitive, communicative, behavioural and social problems that require specialist input from a wide range of rehabilitation disciplines" and the emphasis on interdisciplinary team-working throughout the document. The need for neuro-specific training for healthcare professionals is identified which is positive.
	59	The out-patient services are talked about in terms of 'capacity dependent'. What does this mean?
	63	Voluntary organisations delivering specialist rehabilitation are not considered by the RMP, yet are responsible in a large part for delivering the community neuro-rehabilitation elements of the MoC. They will also undoubtedly be a training resource for the CRTs and PCTs. It is difficult to understand why no consideration has been given to this sector. In the Executive Summary it states "This MoC describes the generic and specialist competencies for staff working in rehabilitative care spanning acute, post-acute and community settings". This cannot be achieved properly without engaging voluntary organisations and outlining how they will be incorporated into the MoC. In terms of the scope of services it states "CRTs will typically comprise the HCSP". It would be useful to have these described more explicitly and who is included here.

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	64	Vocational assessment and rehabilitation mentioned but again not given any weight as the model is exclusively hospital based. There is no clear account as to how this fits within the model and the process of follow-through for the person.
	66	Specialist services for children are mentioned but again there is no full description of these services, nor any clear account of how individuals will move through the services across the lifespan. As such a mention of these services has no meaning and entirely tokenistic in the context of a 'complete MoC. The "transition checklist" (p114) is totally out of place here, has no substance and it is missing some basic elements in its description (who? When does it start?).
	68	There is no mention of the need for PCTs to have training with regard to those with neurological conditions and brain injury so that they can provide appropriate support and recognise when an onward referral to the CRT is appropriate and necessary.

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	70; 81	The document recognises that the realisation of the managed clinical rehabilitation networks will be dependent on the mobilisation of resources and enhancement of service structures as outlined in the neuro-rehabilitation strategy but gives no suggestion or direction how the RMP and the Strategy will interface and work together. In terms of personnel and workforce planning, it is recommended that rehabilitation services at all levels should be led by a consultant in rehabilitation medicine. Currently, voluntary organisations which provide a significant proportion of the services at the proposed level 3 (CRTs) are not consultant led and are frequently staffed solely by allied health professionals and rehabilitation assistant staff. Given that there has been no attempt in the MoC to address voluntary bodies and their role, the document needs to be clearer in relation to how voluntary organisations will be incorporated into the structure of services as a whole, and how the proposed consultant input/leadership will be provided, and indeed, whether this would be appropriate. It is acknowledged elsewhere (page 81) in relation to clinical specialisms that other disciplines may advance to take leadership roles, and it may be necessary and more pragmatic to consider non-medical leadership at level 3 (CRTs) from the outset, given the typical disciplinary makeup at this level within the current service structure.

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	75	This section must include the role of the neuro-psychologist and social worker. Clinical Neuropsychologist As outlined by the American Psychological Association, clinical neuropsychology is a specialty in professional psychology that applies principles of assessment and intervention based on the scientific study of human behaviour as it relates to normal and abnormal functioning of the central nervous system[1]. Clinical neuropsychologists use specialist knowledge in the applied science of brain-behaviour relationships to address neurobehavioural problems related to acquired or developmental disorders of the nervous system (e.g., acquired brain injury). Clinical neuropsychologists are skilled in clinical and neuropsychological assessment, and in the treatment and rehabilitation of behavioural, emotional, psychological, and cognitive sequelae. Competence in neuropsychology requires the ability to integrate neuropsychological findings with neurological and other medical data, psychological and other behavioural data, and knowledge of the neurosciences, and the ability to interpret these findings within the social, cultural, and ethico-legal context in order to formulate tailored, person-centred recommendations for rehabilitation and psychotherapeutic intervention. The role of a clinical neuropsychologist includes: • Utilising specialised assessment techniques and measures to assess intellectual, cognitive, and psychological functioning, • Using clinical and neuropsychological assessment skills to undertake assessment of decision-making capacity, with reference to the legislation, • On the basis of clinical and neuropsychological assessment, formulating person-centred plans for rehabilitation and/or behavioural or psychological interventions.

[1] American Psychological Association (2015). Public Description of Clinical Neuropsychology. http://www.apa.org/ed/graduate/specialize/neuro.aspx

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	75 (continued)	• Utilising specialised, evidence-based intervention techniques (e.g., cognitive behaviour therapy, positive behavioural support), and applying an understanding of the implication of neurological conditions for behaviour and adjustment, as well as culturally apt approaches in neuropsychology, to optimise cognitive rehabilitation and psychological functioning, and to ameliorate behavioural difficulties, ○ Interventions can be undertaken as an individual practitioner (i.e., facilitating individual, group, or family sessions) or within the context of interdisciplinary teamwork (e.g., sharing neuropsychological conceptualisations of neurobehavioural issues with the team in order to formulate rounded interdisciplinary rehabilitation goals, facilitating team reviews of goal attainment, or supervising the work of psychology or rehabilitation assistants) • Selecting and using appropriate, evidence-based measures for measuring rehabilitation/ psychological/ behavioural outcomes • Providing consultation to agencies and individuals (staff members, families and carers) involved in a client's care in relation to neuropsychological, emotional, and behavioural issues, • Facilitating education and awareness seminars for client groups, families, other care and State agencies, or the general public (e.g., in relation to cognitive, emotional, psychological, and behavioural issues that may arise when living with an acquired brain injury and ways of coping with/managing them), • Using training and skills in research design and analysis for service audit, refining evidence-based practice, and contributing to the further development and revision of national policy and models of care.

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	82	The table must include the case manager. In addition, ABI Ireland argues that rehabilitation assistants should form part of the core team and not the ancillary one.
	85	Positive to see reference to the National Standards for Better Safer Healthcare referenced as a structure for clinical governance.
	89	The governance structure is clearly hospital-based and the national system suggested has no interface with the new 9 CHO areas. Neither does it account for the fact that many community-based rehabilitation services are provided by voluntary organisations, nor provide any indication as to how these organisations may be incorporated into the governance structure. Rather it is NRH centric, which is not appropriate given that many individuals will have no relationship with NRH services, particularly those with neurological conditions.
	93	The education and training requirement is viewed very narrowly particularly in relation to who would be involved in the delivery of it. Clearly there is substantial expertise in the NRH but there is significant expertise elsewhere, including the voluntary agencies that are not referenced. For instance, ABI Ireland has provided a number of specialist placements (neuropsychology and rehabilitation in a community service) for clinical psychology doctoral-level trainees, supervised by ABI Ireland clinical neuropsychologists. ABI Ireland clinical neuropsychologists have also provided specialist supervision for doctoral research in neuropsychology and rehabilitation, as well as facilitated lectures/seminars/workshops on neuropsychology and community-based rehabilitation on a number of clinical psychology doctoral courses in Irish universities. ABI Ireland also provides placements for undergraduate level social care students.

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	93	It states that a competency framework for HSCPs will be developed in collaboration with the RMP. This will outline specific competencies that will be considered essential requirements for staff working in the area of specialist rehabilitation. Who is envisaged as the other collaborating parties? Many disciplines already have extant competency frameworks for specialist practice (for instance, clinical neuropsychology), and it is essential that the RMP works closely with the appropriate HSCP professional bodies in agreeing any specialist requirements. It will also involve close working with university course providers at both undergraduate and postgraduate levels in order to ensure that required placements/rotations can be facilitated both within academic courses and practically within services and teams. Again the community setting is being missed here especially when reviewing the training providers as mentioned in the MoC.
	94	While it is very positive that research is suggested as a significant aspect of the MDT, it should also reference the use of the existing research base/best practice/evidenced based practice. There also must be an acknowledgement that high-quality research will require access to protected research time and resources (databases, online journal subscriptions, etc.) and this must be facilitated within the operation of the MDT.
	95	A quality of life outcome measure should be included in the suite identified.
	103	The consultation with service users only references what has happened in the past. This section needs to reflect how the RMP will engage with all stakeholders, in particular service users and their families in an ongoing process. The MoC needs to outline how the RMP will communicate with its stakeholders, for instance, how will it meaningfully engage with service users and what their status will be in terms of the RMP?
	107	The case manager must be named in the pathway. They are a key feature of discharge planning and follow up services and supports.

Name:		**Dr. Sarah Casey, Clinical Neuropsychologist, Caroline Donnellan, Case Manager, Nicola Greene, Senior Occupational Therapist, Donnchadh Whelan, Regional Manager Yvonne Rossiter, Head of Rehabilitation, Grainne McGettrick, Policy and Research Manager**
Organisation:		**Acquired Brain Injury Ireland**
Section number Indicate **section number** or **'general'** if your comment relates to the whole document	**Page Number**	**Comments** Please insert each new comment in a new row.
	108	Pathway 1.1 in Appendix 3 needs discharge planning to be added to it. People with a mild TBI may well need access to services and supports in the community and the pathway should acknowledge this. What about the pathway for the person with a mild TBI who presents at the acute hospital? Case manager referral should be included.

About ABI Ireland

ABI Ireland is a national organisation providing a range of flexible and tailor-made neuro-rehabilitation services and supports to people with an ABI in communities across Ireland. It also works to create awareness of the people living with an ABI, provide information and support to families of survivors. It engages in awareness raising, campaigning, research and advocacy activity to ensure people with ABI and their families have their voices heard.

Contact Details

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