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INSTITUTO UNIVERSITÁRIO  
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DEVELOPMENT AND VALIDATION OF THE ACHIEVED CAPABILITIES  
QUESTIONNAIRE FOR COMMUNITY MENTAL HEALTH (ACQ-CMH)

Beatrice Sacchetto

Tese orientada por Professor Doutor José H. P. Ornelas

ISPA – Instituto Universitário

e co-orientada por Professora Doutora Maria Manuela A. Calheiros

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To all those who seek a better life through the support of community mental health programs

*People have to be seen, in this perspective, as  
being actively involved—given the  
opportunity—in shaping their own destiny, and  
not just as passive recipients of the fruits of  
cunning development programs.*

Sen, 1999, p. 53





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**Palavras-chave:**

Abordagem das capacidades; investigação colaborativa; desenvolvimento e validação de medidas; saúde mental comunitária

**Keywords:**

Capabilities approach; collaborative research; measurement development and validation; community mental health

**Categorias de Classificação da Tese:**

2200 Psychometrics & Statistics & Methodology

2220 Tests & Testing

2222 Developmental Scales & Schedules

2229 Consumer Opinion & Attitude Testing

3300 Health & Mental Health Treatment & Prevention

3360 Health Psychology & Medicine

3365 Promotion & Maintenance of Health & Wellness

3370 Health & Mental Health Services

3373 Community & Social Services



## Prefácio

Esta tese de Doutoramento reflete um trabalho de investigação composto por várias etapas ao longo dos anos e resulta do contributo e da participação de várias pessoas e instituições, pelo que, a sua história merece um destaque específico neste relatório.

A origem da ideia do projeto surge ainda no seguimento do meu trabalho de dissertação no âmbito do Mestrado - sob a orientação da Professora Elena Marta e a co-orientação do Professor Sergio Astori da Universidade Católica de Milão - desenvolvido já em Lisboa, enquanto aluna do programa Erasmus do ISPA-Instituto Universitário. Após ter frequentado várias cadeiras na área da psicologia comunitária com o Professor José Ornelas, escolhi aprofundar o tema da integração comunitária das pessoas com experiência de doença mental. Realizei então, com a preciosa ajuda da Professora Maria João Vargas-Moniz, um estudo empírico com métodos participativos para analisar os ganhos e desafios identificados pelos utilizadores de serviços comunitários de saúde mental, nomeadamente da Associação para o Estudo e Integração Psicossocial e da Recomeço - Associação para a Reabilitação e Integração Social Amadora/Sintra. Os dados recolhidos e resultados alcançados no trabalho de Mestrado foram fundamentais para a continuação da investigação. Foi ainda nesta altura, que tive os primeiros contactos com a abordagem das capacidades e com a Professora Mary Beth Shinn da Vanderbilt University, que continuou a acompanhar o desenvolvimento do projeto, colaborando de forma incisiva em momentos determinantes. A seguir, colaborei como bolsista de investigação num projeto denominado “Fostering Capabilities and Integration of People with Mental Illness”, financiado pela Fundação para a Ciência e Tecnologia (referência PTDC/PSI-PCL/113301/2009), com o Professor José Ornelas como investigador principal e a Professora Mary Beth Shinn como consultora externa. Nesta experiência tive a oportunidade de enriquecer os meus conhecimentos científicos, teóricos e metodológicos, e de afinar o desenho e planeamento do meu projeto de doutoramento. Finalmente, com a obtenção de uma bolsa de Doutoramento da Fundação para a Ciência e Tecnologia, concedida entre 2014 e 2018, consegui desenvolver o projeto delineado, com o devido investimento para realizar as exigentes fases de recolha e análises dos dados.

Assim, o interesse pela abordagem das capacidades foi alimentado ao longo dos anos pelas oportunidades de participação em iniciativas e parcerias científicas. À medida que ia estudando esta teoria, tornava-se sempre mais evidente a sua inovação para promover maior justiça social celebrando a diversidade humana, a sua coerência com os valores e princípios da psicologia comunitária, bem como a sua relevância para a saúde mental. A abordagem das capacidades surge pelo economista Amartya Sen como um indicador alternativo na área do desenvolvimento e foi seguidamente adotada em estudos multidisciplinares sobre a qualidade de vida das populações vulneráveis. As capacidades são definidas como liberdades de escolha e de agência resultantes da combinação das habilidades internas à pessoa e das oportunidades proporcionadas pelo contexto. Neste sentido, o contexto político, social e institucional tem um impacto e papel decisivo na promoção das capacidades individuais, ainda mais, no caso de grupos sociais que vivem situações de desvantagem que podem limitar as suas oportunidades. A filósofa e política Martha Nussbaum propôs uma lista universal de dez capacidades centrais humanas, fortemente inspiradoras para repensar o conceito de qualidade de vida bem como as linhas orientadoras para as políticas públicas e as intervenções sociais. A teoria das capacidades

foi revisitada também por vários autores na área da saúde mental, realçando a sua aplicabilidade para promover o recovery, o empowerment e a integração das pessoas com uma experiência de doença mental. O referencial das capacidades apresenta fortes ligações com a psicologia comunitária, partilhando valores centrais como a autodeterminação, a justiça social e a participação cívica, social e política. Desta forma, a integração e aplicação das duas disciplinas pode fomentar uma mudança transformativa no sistema de saúde mental.

No contexto institucional e político português, a indicação legislativa do Ministério da Saúde (Decreto-Lei n.º 8/2010) define uma série de princípios orientadores para as unidades de cuidados continuados de saúde mental, entre os quais “a promoção da vida independente e de um papel ativo na comunidade”, o “respeito pelos direitos cívicos, políticos, económicos, sociais e culturais para o efetivo exercício da cidadania plena” e objetivos entre os quais “a manutenção ou reforço das competências e capacidades das pessoas com incapacidade psicossocial” (Diário da República, 1.ª série – N.º 19 – 28 de Janeiro de 2010, p. 258). Contudo, os serviços comunitários de saúde mental parecem apelar ainda a modelos médicos e hospitalares, que procuram “recuperar” um “bom funcionamento” das pessoas antes de integrá-las na comunidade, perpetuando fenómenos de institucionalização, controlo e limitação da autonomia e liberdade de escolha.

É a partir destas considerações que se definiu a presente investigação, que tem como principal objetivo o desenvolvimento de um instrumento de avaliação das capacidades alcançadas pel@s utilizador@s de serviços comunitários de saúde mental. Com este instrumento pretende-se avaliar se e em que medida, os serviços de saúde mental de base comunitária proporcionam as condições favoráveis para que as pessoas com experiência de doença mental possam liderar a própria vida e integrar-se na comunidade desempenhando papéis sociais significativos. O desenvolvimento da medida foi realizado com base numa abordagem colaborativa com @s participantes dos serviços, sendo esta metodologia fortemente coerente com os valores da teoria das capacidades, bem como da psicologia comunitária. Além disso, considera-se fundamental e urgente envolver as pessoas com experiência de doença mental na investigação e na avaliação de programas, uma vez que, ao longo da história, elas não têm tido controlo sobre a natureza dos serviços que recebem, bem como sobre a evidência científica que legitima estes mesmos serviços.

O contexto propício das diversas colaborações ao longo dos anos, em particular da parceria academia-comunidade entre o ISPA-IU e a associação AEIPS, favoreceu a realização de uma investigação colaborativa, em particular com membros da Rede Nacional das Pessoas com Experiência de Doença Mental e do Centro de Empowerment e Ajuda Mútua da AEIPS. Desta colaboração em diferentes fases e tarefas de investigação, resultou o questionário das capacidades para a saúde mental comunitária. As etapas seguintes procuraram melhorar e afinar a medida, aferindo a sua validade do ponto de vista ecológico e psicométrico. O presente relatório descreve todo o processo de desenvolvimento e validação do questionário construído neste trabalho de tese, realçando, na sua parte introdutória, as ligações entre os referenciais teóricos e os métodos utilizados. Na parte conclusiva, procura-se evidenciar a relevância dos resultados obtidos para a identificação de um modelo de avaliação e orientação dos serviços comunitários de saúde mental.

O questionário das capacidades proposto neste trabalho de doutoramento pretende servir tanto para @s utilizadores como exercício de reflexão crítica acerca dos seus percursos e dos ganhos alcançados através do suporte recebido, como para os serviços de saúde mental para avaliar e orientar a sua intervenção no sentido de promover a integração e a autodeterminação d@s seus participantes. O processo de desenvolvimento e validação da medida também comportou um processo de adaptação cultural das dez capacidades teorizadas pela autora Nussbaum. A consequente identificação de indicadores e dimensões de capacidades específicas para a população em estudo, representa um framework contextualizado com linhas orientadoras inspiradoras para repensar o sistema de saúde mental.





## RESUMO

A presente Tese de Doutorado, intitulada “Desenvolvimento e Validação do Questionário das Capacidades Alcançadas para a Saúde Mental Comunitária (QCA-SMC)” consiste numa investigação que procura contribuir para a avaliação e inovação dos programas comunitários de saúde mental, através de uma nova medida baseada no referencial teórico das capacidades e construída de forma colaborativa.

Assim, foram definidos dois objetivos principais, nomeadamente: desenvolver uma medida inspirada na abordagem das capacidades, através de um processo colaborativo entre académicos e utilizadores de serviços; validar a medida construída, analisando as qualidades psicométricas e a estrutura fatorial.

Para atingir estes objetivos, foram desenhados estudos e etapas sequenciais com amostras independentes. O primeiro estudo consiste na construção colaborativa do questionário e abrange diversas fases, como a realização de focus group para a recolha dos dados; a constituição de um *steering committee* composto por 3 utilizadores e 2 académico para a análise dos dados e a formulação dos itens; a análise da validade facial com um grupo de 15 utilizadores voluntários. O questionário obtido é composto por 104 itens organizados em 10 capacidades teóricas listadas pela autora Nussbaum. O segundo estudo avaliou a validade de conteúdo envolvendo um painel de 3 utilizadores, 3 profissionais de serviços e 2 académicos, reduzindo a medida para 98 itens. O processo participativo permitiu identificar indicadores relevantes e adequadamente formulados para a população em estudo. Desta forma, promoveu-se a validade ecológica do instrumento, a transformação dos papéis tradicionais de investigação e o empowerment dos/as participantes. No terceiro estudo, foi realizada uma análise fatorial exploratória que permitiu identificar uma estrutura de 6 componentes e 48 itens. Seguiram-se análises de confiabilidade (inclusive test-retest) e validade de constructo, observando a associação com escalas de qualidade de vida, recovery, empowerment e *distress* psicológico. Por fim, no quarto estudo, através da análise fatorial confirmatória, resultou uma solução de 43 itens e 5 dimensões. Realizaram-se análises de confiabilidade, sensibilidade e validade discriminante dos fatores, bem como de validade convergente e divergente. Estes dois últimos estudos revelaram bons resultados psicométricos do QCA-SMC, e possibilitaram uma adaptação das 10 capacidades teóricas, produzindo dimensões relevantes para o contexto que podem ser utilizadas como linhas orientadoras para avaliar em que medida os programas promovem as capacidades das/os suas/seus participantes, bem como para promover uma mudança transformativa do sistema de saúde mental.

O relatório de Tese é composto por três partes principais. A primeira é a Introdução Geral, que realça a) a inovação do referencial teórico das capacidades, tendo em conta o background histórico e atual do sistema de saúde mental, bem como a interligação com a psicologia comunitária; b) a pertinência da abordagem colaborativa na investigação e avaliação na área da saúde mental. Na primeira seção também são apresentados o desenho e o contexto de investigação, os métodos e procedimentos, as medidas e análises aplicadas. A segunda parte consiste na Seção Empírica e apresenta três artigos que refletem os estudos realizados. Por fim, as Conclusões Gerais resumem e discutem os resultados e as suas implicações para uma mudança transformativa, bem como as reflexões sobre limitações e estudos futuros.

**ABSTRACT**

This PhD Thesis, entitled “Development and Validation of the Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH)” consists in a research work that seeks to contribute to the evaluation and innovation of community mental health programs, through a new measure based on the theoretical capabilities framework and developed through collaboration.

Thus, two main aims were defined, namely: the development of a measure inspired by the capabilities approach, through a collaborative process between academics and consumers; the validation of the constructed measure, analyzing its psychometric qualities and factorial structure.

To achieve these aims, sequential studies and steps with independent samples were designed. The first consists in the collaborative construction of the questionnaire and encompasses diverse phases, which focus group sessions for the data collection; the constitution of a steering committee composed of 3 consumers and 2 academics to analyze the data and to formulate the items; the analysis of the face validity with a group of 15 volunteer consumers. The obtained questionnaire is composed of 104 items organized by the 10 theoretical capabilities as listed by Nussbaum. The second study assessed the content validity involving a panel of 3 consumers, 3 service providers and 2 scholars, reducing the measure to 98 items. The participative process allowed to identify relevant and well formulated indicators for the population in study. Thus, the ecological validity of the measure, the transformation of traditional research roles, and participants’ empowerment were achieved. Then, the third study went through an exploratory factor analysis that allowed to identify a structure of 6 components and 48 items. Accordingly, reliability (including test-retest) and construct-related validity were examined, observing the association with scales of quality of life, recovery, empowerment and psychological distress. Finally, the fourth study revealed a 43 items and 5-factors solution through a confirmatory factor analysis. Accordingly, reliability, sensitivity and discriminant validity of the identified factors, as well convergent and divergent validity were tested. These last two studies showed good psychometric outputs of the ACQ-CMH, and allowed an adaptation of the 10 theoretical capabilities, producing context-specific and relevant dimensions, which may be used as guidelines for assessing the extent to which community mental health programs foster consumers capabilities, and for enhancing a transformative change towards the mental health system.

The Thesis is organized by three main parts. The first one is the General Introduction, which highlights a) the innovation of the theoretical capabilities framework, taking into account the historical and current background of the mental health system, as well as the linkage with community psychology; b) the relevance of the collaborative approach for research and evaluation in the mental health field. The first section also presents the research design and context, methods, procedures, measures and analyses. The second part consists in the Empirical Section and reports three articles that reflect the studies carried out. Finally, the General Conclusions summarizes and discusses the main results and its implications for transformative change, as well as reflections about limitations and future studies.

## List of Core Publications

This thesis is based on the three core papers listed below:

- Sacchetto, B.**, Aguiar, R., Vargas-Moniz, M. J., Jorge-Monteiro, M. F., Neves, M. J., Cruz, M. A., ... & Ornelas, J. (2016). The Capabilities Questionnaire for the Community Mental Health Context (CQ-CMH): A measure inspired by the capabilities approach and constructed through consumer–researcher collaboration. *Psychiatric Rehabilitation Journal*, 39(1), 55. doi: 10.1037/prj0000153
- Sacchetto, B.**, Ornelas, J., Calheiros, M. M., & Shinn, M. (2018). Adaptation of Nussbaum's capabilities framework to community mental health: A consumer-based capabilities measure. *American Journal of Community Psychology*, 61(1-2), 32-46. doi: 10.1002/ajcp.12221
- Sacchetto, B.**, Ornelas, J., Calheiros, M. M. (submitted). Confirmatory study of the Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH): A consumer-based outcome Measurement. *American Journal of Community Psychology*.

## Other Publications Related to the Thesis

- Sacchetto, B.**, Ornelas, J., & Calheiros, M. M. (2016). A psicologia comunitária e a abordagem das capacidades. In *Actas do 3º Congresso da Ordem dos Psicólogos Portugueses*, Lisboa, 28 Setembro 2016 a 1 de Outubro 2016 (pp. 748-756). Lisboa: Ordem dos Psicólogos Portugueses.
- Jorge-Monteiro, M. F., Aguiar, R., **Sacchetto, B.**, Vargas-Moniz, M., & Ornelas, J. H. (2014). What transformation? A qualitative study on empowering settings and community mental health organizations. *Global Journal of Community Psychology Practice*, 5(1), 1-13.
- Ornelas, J., Aguiar, R., **Sacchetto, B.**, & Jorge-Monteiro, M. F. (2012). Community-based participatory research: A collaborative study to measure capabilities towards recovery in mental health community organizations. *Psychology, Community & Health*, 1(1), 3-18.



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## **GENERAL INTRODUCTION**



## **1. The Capabilities Approach Contribution for Community Psychology and Community Mental Health**

### **1.1. Community Psychology Perspective towards Community Mental Health**

Historically, the community psychology perspective was developed within a movement of deinstitutionalization that advocated for replacing long-stay psychiatric hospitals with less isolated and more integrated community mental health structures (Shen & Snowden, 2014). Community psychology encloses several principles and values that contribute to the community mental health approach, as recovery and empowerment that appeared within deinstitutionalization initiatives, and represented fundamental concepts for the post-hospital era. The recovery paradigm was introduced by the consumer/survivor movement, who disseminated their personal challenges, experiences and changes. The innovative focus of the recovery concept relies on a process of discovery that involves a new identity instead of a return to previous conditions, and implies hope for the future, self-determination and social connectedness (Ralph, 2000; Ralph & Corrigan, 2005). It marked a significant theoretical revolution, trying to break off with the illness-focused vision of cure, and advocating for equal rights of citizenship and social integration (Deegan, 1988). However, the definition of recovery has become not consensual, and ambiguity about professional role in supporting people with mental illness emerged (Jacobson & Greenley, 2001; Ralph et al., 2002), hindering a clear and efficient implementation of the concept. In fact, psychiatrists and neuroscientists later developed a medical model of recovery, which is based on a clinical evaluation of the illness and symptoms (Lieberman et al., 2008). Therefore, barriers for a system innovation persisted, namely the concept of healing as a requirement for resuming one's life and for accomplishing community integration, and the professional responsibility in made up for peoples' "disabilities".

Empowerment is an interdependent process of recovery, also discussed as a moderator for personal recovery, enclosing components as mastery, control and decision-making power over one's life (Corrigan, 2006). The concept is often confused with other psychological constructs, such as self-esteem, self-efficacy and locus of control. However, empowerment is not reduced to an individual process of power development; it is a multidimensional and multi-level concept, encompassing individual, social and political dimensions, involving a significant relation of mutual learning between the individual and the community (Speer & Peterson,

2000). The empowerment process embeds a critical understanding of one's environment, increasing confidence about individual abilities and agency to contribute to community goals, and promoting social change (Zimmerman, 2000; Zimmerman et al., 1992).

Evidence in the literature points out the need of being involved in the community through meaningful roles and opportunities for recovery and empowerment to occur (Davidson et al., 2009; Ware et al., 2007). Community integration is a core value and goal in community psychology, while in community mental health it has been identified as a priority among researchers and practitioners. Scholars alert that people with mental health problems are often “in the community, but not of it” (Ware et al., 2007, p. 469), and advocate for same opportunities to live and interact in the community as for the general population. The process of integration embeds three components, namely physical, psychological and social, underlining the co-presence of be in the community using its resources; develop regular interactions and meaningful relationships; feel sense of belonging, emotional connections and capacities for influencing (Wong & Solomon, 2002). Social support has been identified as promoting community integration with impacts in individual well-being. A comprehensive understanding of the concept of social support involves diverse components, namely emotional, tangible and informational aid, as well as social activities and networks perceived as beneficial and supportive to foster community integration (Terry & Townley, 2019). This kind of support may be provided by informal natural helpers, like relatives, friends or neighbors, as well as by formal contexts like organizations, services and professionals. Positive social support provided by both informal and formal settings, has been identified as a key factor for integration and recovery (Townley et al., 2013).

All the values and concepts mentioned above evoke a central role of individuals' participation and engagement within the community life, reflecting the principal standpoint of community psychology that is the contextualist and ecological epistemology. The ecological theory stresses the interdependence of individuals with their social environments, moving the emphasis from people's deficits to context features. Taking environment into account means looking at the personal, interpersonal, organizational/institutional settings, as well as historical, cultural, economic, and political dimensions that shape one's life (Kelly, 2006; Kelly, 2010). Environment is a key variable for community psychology practice and research, as it may either facilitate or hinder the process of social participation and integration.

Community psychology principles, like empowerment, recovery and community integration are stated in international and national policy recommendations for the community

mental health system (see Green Paper on Mental Health, European Commission, 2005; *Proposta de Plano de Acção para a Reestruturação e Desenvolvimento dos Serviços de Saúde Mental em Portugal 2007-2016*, Caldas de Almeida et al., 2007). However, community mental health practice often fails in the application of these values, by providing settings designed exclusively for people with mental illness experience, misplacing effective social integration, and consequently, empowerment and recovery promotion.

## **1.2. Community Mental Health Practice: An Overview**

Community mental health programs are context of support for people with mental illness experience that should provide alternatives to socially segregated environments; otherwise, a process of transinstitutionalisation would take place - i.e. the reproduction of the institutional *modus operandi* (Nelson et al., 2014). However, looking at the post-deinstitutionalization mental health response, a long-term rehabilitative approach has spread and dominated the community mental health system (Shen & Snowden, 2014). The so called “vocational-rehabilitation programs” are often supplied through activities to spend time, without an effective purpose of integration (Evans et al., 2012). These interventions aim mostly at illness management, as reducing hospitalizations and symptoms, and provide training life skills and daily activities (e.g. artistic or physical activities). A common model of intervention among rehabilitation programs is the “stair case model” that postulate a gradual training until a supposed readiness is achieved for the transition to the community. Consequently, life in artificial environments is perpetuated. Research has showed that competences are not transferable; therefore, the previous training is not effective for the life experience in natural contexts (Corrigan & McCracken, 2005). Moreover, this model implies a constant psychological assessment of consumers carried out by professionals, mostly considering their symptoms. A divergent model of intervention based on community psychology is the so called “intervention-first approach” (Ornelas et al., 2019). This model relies on the assumption that recovery as a personal process is only possible if people are involved in natural community contexts and have concrete opportunities for participation (Davidson et al., 2009).

A brief analysis of current models of community mental health interventions is here presented, with a specific focus on employment and housing, which represent two crucial areas of intervention and human rights, as recognized also by the European Pillar of Social Rights (European Parliament, 2017). About employment, professional integration is urgent for people

with mental health problems, once they suffer high rates of unemployment (Kinoshita et al., 2013). However, vocational-rehabilitation programs often provide models of “sheltered employment” that consist in working experiences within protected environments like social firms of manufacturing or catering (Eklund & Sandlund, 2012). In other terms, it consists in pre-established programs within artificial settings where consumers’ interests and choices are scarcely considered. On the other hand, the model of “supported employment” is based on community psychology principles and strives for working opportunities in the open labor market available to all citizens (Drake et al., 2012). It looks for a matching between consumers’ interest and abilities with job types within competitive companies. The participation in regular employment environments has been identified as positively correlated with empowerment and recovery promotion (Dunn et al., 2012; Sá-Fernandes et al., 2018), increasing self-esteem and life satisfaction (Luciano et al., 2014).

The equivalent community psychology approach regarding housing is the “independent housing” model, in contrast with the residence model of “group homes” provided by the rehabilitative approach. Particularly, “housing first” is a program that combines the access to independent and permanent housing with flexible consumer-driven support services (Tsemberis et al., 2004). Research shows that the independent housing scattered in regular community settings provides better outputs in terms of perceived choice and quality of life when compared with congregate residential programs (Cheng et al., 2007). Higher rates of empowerment and recovery have been also observed in a national study for consumers who live in independent housing than those who live in group homes or with their relatives (Jorge-Monteiro & Ornelas, 2016a). Moreover, independent housing has been associated with better community integration, especially considering the psychological and social dimension, as well as with sense of belonging to the community and social connectedness (Gulcur et al., 2007; Ornelas et al., 2014).

An effective application of community psychology values entails a shift from segregation to integration in natural community contexts, as in the case of supported employment and independent housing models. A further step supported by concrete and innovative guidelines for practice and research may inspire the community mental health system towards a transformation. In this sense, the capabilities framework has been proposed as the required tool to move from clinical and illness-focused to agent-centered approaches (Davidson et al., 2009; Hopper, 2007; Shinn, 2015).



### **1.3. Capabilities Approach and Community Psychology: The Common Ground**

People with mental health issues face personal challenges and social barriers, however, these factors do not alter the human nature of self-determination and freedom of choice. Thus, they have the right to opt within a bunch of diverse social activities and roles. This should have been the path of community mental health structures in the post-hospital era, since the main problem of institutionalization was the lack of freedom and autonomy (Deegan, 1992). A theoretical account that fosters a paradigm change, restoring consumer agency and self-determination, is of major interest. In this sense, this PhD work proposes the application of the capabilities approach (Nussbaum & Sen, 1993), as a new inspiring framework for community mental health.

The capabilities approach has been initially developed within welfare economics by the economist Amartya Sen, who defined capabilities as substantive freedoms or opportunities to act and choose (Sen, 1992; 1999). Sen elaborated the Human Development Index (HDI) that was adopted within the annual reports of the United Nation for Human Development Program (UNDP), and deserved a Nobel Prize in 1998. The author collaborated with the philosopher and political Martha Nussbaum to elaborate on quality of life studies and social justice (Nussbaum & Sen, 1993). They worked particularly on poverty and hunger, introducing an innovative perspective that focuses on inequality of access instead of lack of resources.

The originality of the capabilities approach consists in the redefinition of peoples' necessities, as well as the standards to measure quality of life. What matters is the individual choice within "beings" and "doings" people value. When achieved, these capabilities are also called as "functionings", representing doings and beings that individuals choose and realize, making its life worth living. Capability is not intended as an intraindividual concept; rather it refers to the notion of "combined capabilities", encompassing both personal capacities and contextual arrangements. In this sense, this approach suggests the need to look beyond material deprivations to social and political lacks, and to switch from resources to what people are able to do or to be. This theoretical framework recalls the ecological approach within community psychology, which underlines the interdependence between individual and environment. So, the capabilities approach and community psychology share the same underlying societal perspective, enclosing an understanding of people as social beings within interpersonal, social, institutional, and political networks (Kelly, 2006; Sen, 2009). In this sense, an in-depth multilevel analysis of one's environment and its impacts in individual opportunities is essential, particularly for people in a disadvantaged situation. Social groups affected by social exclusion

and discrimination, may suffer a capabilities deprivation, interfering with the ability to make valued choices and to fully participate in the society. The focus on individual freedom and choice helps to emphasize the context responsibility, pointing out to the system features, as social, policy and economic facilities that are provided - or not - to people. In fact, socially excluded groups need more institutional aids and supports to achieve what they desire than people without vulnerable social conditions (Shinn, 2015), due to the absence of favorable circumstances. Taking capabilities seriously means provide spaces where not-conventional possibilities might flourish. A capabilities-informed system may search for “what enables people to thrive, not to survive [...] more than kindly attitudes and respectful posture will be needed [...] real opportunities for exercising self-determination and making informed life-changing commitments” (Hopper, 2007, p. 875). Therefore, success in addressing disability or mental health challenges depends upon whether social barriers can be converted into supportive environments to exercise meaningful roles and activities within the community.

Another crucial concept of the capabilities theory is agency (Sen, 2004), i.e. individuals’ leadership and concrete action of choosing and enacting possibilities. In the area of mental health, individual’s agency is fundamental, since people with mental illness have suffered a position of dependency on the system (Nelson et al., 2001). This concept is coherent with community mental health models based on community psychology principles. For instance, the focus on individual agency converges with empowerment’s value of decision-making power, and with the self-determination goal of the recovery process, but is even more consistent, once it directs attention to the lack of social and material conditions to achieve full civic participation (Shinn, 2015). The capabilities approach may convert recovery ambiguities - due to different definitions of the concept than the initial one stemmed by the survivor/consumer movement - into a more solid framework for mental health. Capabilities clearly focus on the right of choice made by individuals themselves, avoiding a professional-led decision-making process. Instead, professionals within formal context of social support should centralize their intervention in providing opportunities of full social participation without preconditions or “some mythical later time” (Davison et al., 2009, p.41) of readiness. The capabilities approach suggests that the free exercise of choosing and enacting the chosen options, fulfill the human nature (O’Connell & Davidson, 2010).

Beyond the above-mentioned conceptual links, the capabilities and the community psychology frameworks share underlining values, like social justice and respect for human diversity (Dalton et al., 2001; Nussbaum & Sen, 1993). Regarding social justice, both

theoretical approaches advocate for an equal and fair access to resources, opportunities, rights and obligations for all members of society. While human diversity celebrates the multiplicity of the communities, based on different intersectional factors like gender, age, nationality, sexual orientation, socioeconomic status, as well as personal life experiences. The respect for diversity is expressed in searching for strengths and resources among all communities, cultures and marginalized populations.

Considering this common theoretical grounding, community psychologists are in a favorable condition to translate the capabilities framework into innovative practice and research, applying an ecological and contextual analysis of people within their environments, in order to reverse social inequalities towards social fairness. Besides, the implementation of an empowering attitude will facilitate the professional endeavor in supporting consumers to define and lead their own recovery process.

#### **1.4. Nussbaum's Capabilities Account and its Relevance for Mental Health**

Martha Nussbaum (2000; 2011) developed on the capabilities approach and applied it in studies on women in developing countries, whose life opportunities are reduced. Basing on cross-cultural studies, she drew up a list of ten central human capabilities concerning economic, political, social and civic liberties (Nussbaum, 2000). The author sustains that her account works for every human being, as grounding to assess and compare quality of life, as well as for every nation to orient public policies (Nussbaum, 2008). Capabilities are intended as innate and universal; every human being should have the opportunity to flourish its inner potential. However, her proposal of ten capabilities is only a starting point, thus, "each nation must and should describe the capabilities it pursues more concretely, using their own history and traditions as a guide" (Nussbaum, 2011, p. 29). Table 1 shows Nussbaum's list of ten central human capabilities and its definitions.

Strong theoretical coherences between Nussbaum capabilities dimensions and community psychology can be identified, as well as its relevance for the mental health field, endorsing its application for the orientation of social programs. A brief description of each capability based on Nussbaum's definitions, as well as its significance for the population of people with mental illness experience, will be presented justifying the adoption of this theoretical approach for the group in study.

Table 1  
*The Central Human Capabilities*

Capability	Description
Life	Be able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
Bodily Health	Being able to have good health, including reproductive health, to be adequately nourished; to have adequate shelter.
Bodily Integrity	Being able to move freely from place to place; being able to be secure against assault, including sexual assault, child sexual abuse, and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
Senses, Imagination and Thoughts	Being able to use the senses, to imagine, think and reason – and to do these things in a “truly human” way, informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing self-expressive works and events. Freedom of expression. Being able to search for the ultimate meaning of life in one's own way. Being able to have pleasurable experiences, and to avoid non-necessary pain.
Emotions	Being able to have attachments to things and people outside ourselves; to love and grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by overwhelming fear and anxiety, or by traumatic events of abuse or neglect.
Practical Reason	Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (the liberty of conscience)
Affiliation	<p>a) Being able to live with and towards others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another and to have compassion for that situation; to have the capability for both justice and friendship. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)</p> <p>b) Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails, at a minimum, protections against discrimination on the basis of race, sex, sexual orientation, religion, caste, ethnicity, or national origin. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.”</p>
Other Species	Being able to live with concern for and in relation to animals, plants and the world of nature.
Play	Being able to laugh, to play, to enjoy recreational activities.
Control over one's Environment	<p>a) <i>Political</i> - Being able to participate effectively in political choices that govern one's life; having the right to political participation, protections of free speech association.</p> <p>b) <i>Material</i> - “Being able to hold property (both land and movable goods, not just formally but in terms of real opportunity; and having property rights on an equal</p>

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basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure.

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*Note.* Adapted from Nussbaum (2000).

The first capability is called “Life” and is defined as “Being able to live... [a] life of normal length; not dying prematurely”, (Nussbaum 2000, p. 78), while the second one is “Bodily Health” and is about “Being able to have good health, including reproductive health, to be adequately nourished; to have adequate shelter” (Nussbaum 2000, p. 78). Health disparities are a common concern for socially excluded groups. Specially, consumers of the mental health system present a twice rates mortality and, on average, 25 years less longevity than the general population, where 60% of premature deaths are due to medical issues such as cardiovascular diseases, hypertension and diabetes (Colton & Manderscheid, 2006). This social group has an increased risk of physical diseases related to sedentary behaviors and psychiatric medication, which causes weight gain among other side effects (Parks et al., 2006). Therefore, physical well-being, healthy lifestyle and habits are quite relevant for people with mental health issues.

“Bodily Integrity” is the third capability and is defined by Nussbaum as “Being able to move freely from place to place; having one’s bodily boundaries treated as sovereign, i.e. being able to be secure against assault...” (Nussbaum 2000, p. 78). People with mental health challenges often suffer from social discrimination, which may involve episodes of violence and/or harassment (Khalifeh et al., 2016). In some cases, these events led to the necessity of moving home (Barnes & Bowl, 2001), affecting severely personal security and freedom of movement.

The fourth capability is called “Senses, Imagination and Thought” and is described as “Being able to use the senses, to imagine, think and reason ... in a truly human way... informed and cultivated by an adequate education” (Nussbaum 2000, p. 79). This dimension is relevant considering the lack of school and educational opportunities provided to people with mental health problems (Megivern et al., 2003; Ware et al., 2008). This population often have not completed their studies, which affect future employability (Burke-Miller et al., 2006).

“Emotions” – which is the fifth capability - is explained in Nussbaum work as “Being able to have attachments to things and people outside ourselves, ...to love, to grieve, to experience longing, gratitude, and justified anger” (Nussbaum 2000, p. 79). While “Affiliation” – which is the seventh capability - is defined in two sub-dimensions, namely a) “Being able to

live with and towards others, to recognize and show concern for other human beings;" b) "Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others" (Nussbaum 2000, pp. 79-80). These two capabilities are presented together, as they fully match with community psychology concepts of social support and community integration that have decisive impacts on consumers' recovery and well-being (Terry & Townley, 2019). Positive attachments and relationships of respect and non-humiliation may be complex capabilities for people with mental illness experience, since discrimination still persists in society. Even familiars and relatives often reveal stigma towards mental illness, focusing more on limitations than on abilities, hindering the process of integration and recovery (Hamilton et al., 2016). Negative social support - i.e. not necessary, wanted, or not coherent with individuals' needs - has showed harmful consequences in individual well-being (Ray, 1992). Therefore, mental health services may address two aspects to enhance these capabilities: design its intervention basing on individuals' needs and interests; foster the development of supportive and empowering relationships within different ecological levels of individuals' lives, like the personal, interpersonal, organizational/institutional and social ones.

"Being able to form a conception of the good and to engage in critical reflection about the planning of one's life" (Nussbaum 2000, p. 79) is Nussbaum's definition about the sixth capability, named "Practical Reason". Historically, people with mental health problems have been seen as unpredictable, irrational and, consequently, unable to manage their own lives, causing a significant social prejudice and discrimination (Thornicroft et al., 2007). Conversely, research findings on empowerment in mental health demonstrate that critical reflection, planning about one's life, and decision-making power, are crucial vehicles to trigger the empowerment process (Corrigan, 2006; Speer & Peterson, 2000).

"Other species" - "Being able to live with concern for and in relation to animals, plants and the world of nature" (Nussbaum 2000, p. 80) - is the eighth capability and "Play" - "Being able to laugh, to play, to enjoy recreational activities" (Nussbaum 2000, p. 80) - is the ninth dimension. Exposure to natural environment and interaction with nature is associated with better mental health outcomes and lower levels of stress (Pearson & Craig, 2014). Both capabilities may be included in further studies and interventions to explore its role in consumers' lives and recovery processes.

Finally, the tenth capability listed in Nussbaum work is "Control over One's environment" and comprises two aspects: a) "Political" that is about "Being able to participate

effectively in political choices that govern one's life; having the right to political participation ... free speech and association;" and b) "Material" that is described as "Being able to hold property... having the right to seek employment on an equal basis with others" (Nussbaum, 2000, p. 80). The belief that people with mental illness have to reach some "mythical later time" to be able to resume their own lives still persist, although authors remark that there are no preconditions for the exercise of a full citizenship with material, social, civic and political rights (Davidson et al., 2009; Ware et al., 2007). The material component of this capability refers to the right to hold property and to access an equal distribution of income than for the general population (Shinn, 2015). While the political aspect of this capability recalls empowerment and more concretely, consumers' participation right through formal roles of influence (Piat & Polvere, 2014). Moreover, a political control in the mental health field evokes advocacy and peer support activities, such as mutual aid groups, consumer-led services and employing mental health consumers as providers, which show a crucial role to foster recovery and empowerment (Davidson et al., 1999; Munn-Giddings & Borkman, 2017).

In conclusion, Nussbaum's capabilities list covers diverse dimensions including primary goods, such as health, material and cultural necessities, and more complex capabilities, like critical reflection, the exercise of control and social connectedness. The mental health system may inspire on these dimensions to develop strong guidelines for community programs and services, considering that people with mental illness experience need institutional and political support "to overcome differences arising from persistent social inequalities" (Shinn, 2015, p.244). Community-based mental health initiatives should focus on the promotion of supportive environments and solid bonds between people and community settings, in order to enable the exercise of complex capabilities, as self-determination, practical reason, and affiliation (Nussbaum 2000, 2011).

For this purpose, community mental health interventions are recommended to be evaluated through a capabilities-oriented measure (Jorge-Monteiro & Ornelas, 2016a), in order to assess the extent to which programs are enhancing consumers' capabilities. The present thesis explores and applies the capabilities approach, in order to develop a specific instrument that may orient community mental health interventions and evaluation. At the same time, the process for the development of the research measure has been carried out in line with this agent-focused approach.

## **2. Evaluation and Measurement through a Collaborative and Capabilities Orientation**

### **2.1. Research Procedures: Lessons from The Collaborative Approach**

Beyond the application of the capabilities framework for community mental health, this PhD thesis pursues the adoption of innovative processes of research that reflect values of both the capabilities and community psychology approaches. Traditionally, community psychology focuses on the development of adequate methods and strategies to advance bonds between science and practice towards more community centered research models (Wandersman et al., 2005). Particular emphasis is placed on the application of “collaboration and community strength”, which is considered the most distinctive value of community psychology research and intervention to better understand and enhance quality of life for individuals, communities and society (Dalton et al., 2001). Collaboration is also deeply connected with the ecological perspective. The ecological and collaborative rationales are both grounded on contextualism, which indicates that “knowledge is relative to a given empirical and theoretical frame of reference and that we are implicitly embedded in the world we observe” (Kelly, 2006, p.171). Collaboration in community practice and inquiry undertakes a transition from the individual level to the community one, taking into account historical, cultural, economic and political constraints and forces (Espino & Trickett, 2008). This principle is expressed in the relationship between community psychologists and members of the community with whom they work, where the experience of community members is considered as important as the professional or academic one, since both contribute with knowledge and resources. It legitimizes “the inclusion of diverse voices, based on gender, race, age, ethnicity, class, and so on, into the research process, because to do so is to do better science” (Tebes, 2005, p. 222). Moreover, commitment and reciprocity have been identified as core features of the collaborative relation, which enhance an in-depth understanding of the culture of the community, embedding its background, norms, roles, and areas of expertise.

The collaborative approach contrasts traditionally positivist research methods, where researchers enter a community, collect and analyze data, without involving community members. “This kind of research can be exploitative, benefiting only the researcher and giving nothing back to the community” (Riger, 2001, p.46-47). Whereas principal characteristics for a collaborative research are the definition of goals based on the needs of the community, parity



among participants, shared resources and responsibilities (Ochocka et al., 2002). The establishment of open lines of a communication system, based on trust and mutual respect, is also essential since it allows to clarify expectations and to construct a common vision of goals. The collaborative model is identified as a two-way learning relation, being characterized by mutual learning, influence and co-empowerment (Fetterman, 2015).

Participatory dynamics are applied throughout the diverse research tasks to settle goals, techniques of data-gathering and analysis, and to better understand and use research findings (Prilleltensky & Nelson, 2002). This process ensures the ecological validity of the produced knowledge, i.e. the meaningfulness, usefulness and sustainability for the group in study (Trickett & Espino, 2004). A framework for university-community partnership has been elaborated by Suarez-Balcazar et al. (2004) where several features for a successful collaborative research process are stated. Some of these characteristics are listed hereafter, which are considered the most innovative elements in research, particularly for socially excluded groups, since their role and contribution has been traditionally underestimated. To "understand the multidisciplinary nature of partnerships" involving individuals from different disciplinary backgrounds, as well individuals with diverse cultural and historical experiences; to "respect and celebrate diversity", which includes the development and use of culturally sensitive and adequate research instruments; to "maximize, use, and exchange resources", such as grant funding, technology, research literature and methods, in order to create a balanced relationship; to "share accountability of partnership success and opportunities", for instance, working together for reports and dissemination activities in academic and community fields.

Collaborative research has been recommended to examine strengths and weakness within social integration, especially for disadvantaged groups (Bond & Keys, 1993). Members of these groups need to be well represented in the research endeavor. In this sense, the creation of specific structures as central vehicles to ensure participation have been identified. For instance, a research team responsible to carry out the research tasks, both collecting and analyzing, and/or a research steering committee to supervise the research development, and to make decisions through negotiation and consensus (Nelson et al., 1998).

The collaborative approach is particularly relevant for mental health, considering that the people with lived experience have been historically silenced in both practice and research.

## **2.2. Collaboration in Evaluation and Measurement**

Evaluation is defined as a process of reflection whereby the value of certain actions in relation to projects, programs, or policies is assessed (Springett & Wallerstein, 2008). Evaluation through participatory procedures promotes the development of local theory within the context of intervention. All partners contribute to the creation of knowledge in a systematic inquiry based on their own categories and frameworks. Participatory processes in research and evaluation ensures that the identified indicators measure the right questions, that is, meaningful to the local community (Wright et al., 2018). In other words, the ecological validity of the produced knowledge is ensured.

Literature within this topic evidences diverse labelling that reflect some differences in practice, as “democratic evaluation” and “empowerment evaluation” (Fetterman, 2015). The common feature for participatory models of evaluation is the involvement of marginalized groups to foster their capacity of dialogue and critical reflection (Themessl-Huber, 2003). Regarding mental health, consumers’ involvement in service evaluation, as well as in the development of new outcome measures, is quite scarce. As a result, the definition of outcomes often do not represent consumers’ meanings of gains and goals (Rose, 2015). In this sense, an in-depth exploration of meanings of service outcomes for people with mental health issues is compelling. Moreover, collaborative processes for the development of research instruments, especially concerning quality of life, are highly recommended (Thorncroft & Tansella, 2010).

Evidence in the literature also points out the importance of patient reported outcome measures to improve consumers’ satisfaction, by participating in the assessment of the impacts of the intervention on their lives, instead of being assessed by professionals. Patient reported outcome measures are largely used in mental health research, especially for quality of life assessment, but most fail to identify non-health outputs. Considering that the population of people with mental health problems is affected by poor economic and social outcomes, beyond scarce health conditions (Brunner, 2017), multi-dimensional instruments are recommended, in order to cover broader domains of quality of life and well-being. In this sense, a capabilities-oriented measure may offer an adequate broader multidimensional approach.

## **2.3. New Capabilities Oriented Measures for Health and Mental Health**

The capabilities approach by Amartya Sen and Martha Nussbaum (Nussbaum & Sen, 1993) has gained visibility among interdisciplinary studies, leading to a growing interest in

operationalizing this approach to measure quality of life. Particularly, the application of the capabilities framework has increased in the field of public health, inspiring the development of new measures. Recent literature reviews on capabilities measurement reported that several new instruments have been developed in the last decade for the evaluation of health and social care interventions (Helter et al., 2020; Til et al., Under Review). These new evaluative measures pursue an alternative framework for the assessment of interventions in regard to non-health effects and broader elements of quality of life and well-being (Mitchell et al., 2017). Different kind of tools for measurement have been developed, encompassing qualitative, quantitative and multi-methods instruments. Table 2, retrieved from the most recent systematic review of measurement in health (Till et al., Under Review), shows the authors that report on the development of the respective tool. Below, each of the quantitative self-reported instruments are briefly described.

Table 2

*Capabilities Measurement Tools in the Health field.*

Capabilities Measurement Tool		Reference
Qualitative Tools	Interviews	Sauter, Curbach, Rueter, Lindacher & Loss (2019) Weaver, Lemonde, Payman & Goodman (2014) Ndomoto et al., (2018)
	Videography	Petros, Solomon, Linz, DeCesaris & Hanrahan (2016)
Mixed Method	Questionnaire and Interviews	Bucki, Spitz, Etienne, Bihan & Baumann (2016)
Quantitative Questionnaires	ICECAP	ICECAP-O ICECAP- A ICECAP-SCM ICECAP-FC
		Coast et al., (2008) Al-Janabi, Flynn & Coast (2012) Sutton & Coast (2014) Al-Janabi (2018)
	OCAP	OCAP OCAP-18
		Anand et al., (2009) Lorgelly, Lorimer, Fenwick, Briggs & Anand (2015)
	OxCAP-MH	Simon, Anand, Gray, Rugkåsa, Yeeles & Burns (2013)
	CQ-CMH	CQ-CMH ACQ-CMH
		Sacchetto et al., (2016) Sacchetto, Ornelas, Calheiros & Shinn (2018)

Capability-based questionnaire in patients with chronic pain	Kinghorn, Robinson & Smith (2015)
CADA	Ferrer, Cruz, Burge, Bayles & Castilla (2014)

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*Note:* Adapted from Till, Abu-Omar, Ferschl, Reimers & Gelius (Under Review).

The ICECAP is a measure of capability for use in economic evaluation and consists in a set of index value to capture a broader concept of wellbeing. It has been adapted to different target groups, where capabilities attributes are modified basing on participatory procedures with members of the group in study. Items ask if respondents are able to achieve each of the capabilities domains using a 4-point rating scale (i.e. the number of attributes correspond to the number of items of the measure). The ICECAP-A (Al-Janabi et al., 2012) is a tool for the general adult (18+) population. Interviews with a sample of adults in England were conducted to explore attributes of capabilities. Specifically, five domains were identified, i.e. Attachment, Stability, Achievement, Enjoyment, and Autonomy. The ICECAP-FC (Al-Janabi, 2018) is a variation of the previous measure, where adults are asked about both capabilities and functionings for comparative purpose (i.e. ability to achieve capabilities *versus* achieved capabilities). The ICECAP-O (Coast et al., 2008) consists in a specific version of the ICECAP for older people (over 65 years) that has refined the measure terminology and attributes through a qualitative process with a sample of informants. It entails five dimensions, namely, Attachment, Security, Role, Enjoyment, and Control. Finally, the ICECAP Supportive Care Measure (ICECAP-SCM) (Sutton & Coast, 2014) is as a tool for use in economic evaluation conducted in an end of life setting. For the measure adaptation, interviews with a group of patients, close persons and healthcare professionals were conducted. As a result, seven dimensions were proposed, i.e. Choice, Love and affection, Physical Suffering, Emotional Suffering, Dignity, Being Supported, and Preparation.

The Capability-Based Questionnaire for Assessing Well-Being in Patients with Chronic Pain (Kinghorn et al., 2015) was developed through focus groups and interviews to identify a list of capabilities considered important to those with chronic pain. Eight dimensions were identified, i.e. Love and social inclusion; Enjoyment; Respect and Identity; Remaining Physically and Mentally Active; Independence and Autonomy; Societal and Family Roles; Physical and Mental Well-being; Feeling Secure about the Future. The way of response is the

same of the previous ICECAP, i.e. respondents are asked if they are able or not to achieve the identified capabilities domains using a 4-point rating scale.

The Capability Assessment for Diet and Activity (CADA) (Ferrer et al., 2014) was constructed basing on a community-based participatory model. Focus groups of adults with obesity or diabetes mellitus from an economically disadvantaged Latino community were organized. A pool of 120 items resulted from the focus group data analysis. Later quantitative study with EFA showed 35 items distributed within 8 subscales, namely, Convenience-Cost, Neighborhood Opportunity, Barriers, Knowledge, Time Pressure, Family Support, Spouse/Partner, Non-family Support.

Finally, considering the health field, the OCAP (Oxford Capability Questionnaire) (Anand et al., 2009) is a measure that assesses Nussbaum's ten central human capabilities with 64 items. Participatory procedures, such as focus group and interviews, have reduced the measure to a new version composed of 18 indicators, called OCAP-18 (Lorgelly et al., 2015), where each of the ten capabilities of Nussbaum list are assessed by one or more items.

Regarding the mental health field, several non-health outcomes are considered essential for the population of people with mental health challenges, like recovery, empowerment, self-determination and autonomy, social relationships and integration, hope and optimism about the future. In terms of capabilities measurement, beyond the measure developed and validated within this PhD work, one more quantitative instrument has been identified so far (Helter et al., 2020; Till et al, Under Review), which is called the Oxford Capabilities Questionnaire for Mental Health (OxCAP-MH) (Simon et al., 2013). The OxCAP-MH is an adaptation of the OCAP-18 measure, obtained through “expert focus group discussions involving psychiatrists, psychologists, social scientists and health economists” (Simon et al., 2013, p.189). The OxCAP-MH consists in a 16-item index including the following domains: Overall Health, Enjoying Social and Recreational Activities, Losing Sleep over Worry, Friendship and Support, Having Suitable Accommodation, Feeling Safe, Likelihood of Discrimination and Assault, Freedom of Personal and Artistic Expression, Appreciation of Nature, Self-determination and Access to Interesting Activities or Employment.. The measure presents evidence of psychometric studies (Łaszewska et al., 2019; Vergunst et al., 2017), but failed in terms of ecological validity, since it did not include consumers’ perspective and their meanings about capabilities and outcomes in the development process. In this sense, the produced knowledge is based on expert’s perspective, where expertise is (wrongly) intended in the sense professional and academic status.

Research findings alert about the possibility of misunderstanding about the meaning of service outcome and quality of life results, if people to whom the service is addressed are not engaged in the evaluation processes (Rose et al., 2011; Thornicroft & Tansella, 2010). Moreover, capabilities authors also advocate the use of participatory methods in identifying valuable capabilities with those affected by a policy or intervention (Alkire, 2008; Robeyns, 2005).

Therefore, a research instrument inspired by the capabilities approach and based on consumers' perspective - i.e. constructed in collaboration with people with the lived experience of mental illness and service participation - seems to be required to fulfill this lack in mental health research and evaluation.

#### **2.4. Development and Validation of New Measures**

Regarding measurement, new developed research instruments need to report psychometric properties, in order to be generalizable and replicable in research, as well as to be adequately chosen for evaluation in service routine. Recommendations for best practices in the development and validation of new measures indicate three crucial phases (Boateng et al., 2018). The first one encloses the generation of items and the assessment of the content validity. For item generation, attention has to be paid to an accurate description of the domains based on literature; the definition of adequate questions to address the identified domains; and explorative methods to generate discussion and data, as focus groups (DeVellis, 2016). Content validity is the estimation of each item in terms of content relevance, representativeness, and technical quality, assessed by a panel of expert judges through quantified indices like the content validity index. The second phase concerns the administration of the scale, the item reduction and factors extraction through exploratory factor analysis. About sampling, between 200 and 300 participants is considered an appropriate sample size for factor analysis (Guadagnoli & Velicer, 1988). The third and last phase is about scale evaluation, to validate whether the previous hypothetical structure is adequate. In this sense, the latent structure of the measure and the underlying relations between items are examined through confirmatory factor analysis. Moreover, psychometric properties need to be tested, namely reliability and validity. Reliability captures the capacity of the instrument to consistently measure the construct. Common tests for reliability are the internal consistency of a scale, examined across items, and the test-retest to observe cohesion over time. Considering validity, it indicates the extent to which a concept is accurately measured, including convergent validity, to analyze if two related

concepts are statistically associated, and discriminant validity, to examine if the construct diverges from a not related concept.

Finally, transcultural multi-site studies are recommended, through adequate processes of translation and adaption (Beaton et al., 2000), in order to test the measure in different settings and languages, as well as to compare data across countries.

### **3. Rational and Methods of the Thesis**

As illustrated in the previous sections, the mental health system is still dominated by a medically-oriented approach, which tends to keep the focus on individuals' clinical conditions like illness and symptoms, causing discrimination and social exclusion. A community-based system of support should define and implement its own models of practice, research and evaluation based on a multi-level and multidimensional perspective, to provide an efficient alternative in mental health, focusing on a clear and unambiguous mission, which is the promotion of an integrated and dignify life in the community made up of social, civil and political rights.

In this sense, the main scientific interest of the present thesis is to identify an innovative framework for community mental health based on the capabilities approach, which is considered coherent with the community psychology perspective, with innovative implications for social policies, programs orientation and professional attitude.

#### **3.1. Research Aims and Design**

The purpose of this PhD work is to provide a new research framework for the orientation and evaluation of community mental health programs, and more in general, for influencing the mental health system. At the same time, it is intent to use a collaborative approach throughout the research. Therefore, a two-fold goal has been defined: first, to develop a measure inspired by the capabilities theory in strict collaboration with consumers of community mental health services, and second, to validate it.

In detail, these two subsequent goals are:

- a) The development of a measure, inspired by the capabilities approach, through a collaboration between researchers and community mental health consumers, providing

that way the ecological validity of the measure and an empowering collaborative partnership. The collaborative method has been chosen to ensure the identification of a consumer-valued framework with specific dimensions and indicators of capabilities to be used for programs evaluation. In this sense, community mental health programs may assess its results, and plan its intervention, basing on the achievement of consumers' capabilities.

- b) The validation of the previous developed measure examining its psychometric properties, comprising the content validity to check the adequacy and relevance of the measure construct, the reliability including a test-retest, and the factorial structure, in order to identify context-specific dimensions and indicators of capabilities for the community mental health context, and to provide a robust evaluative framework for outcome measurement; specifically, to evaluate the extent to which mental health programs foster consumers' capabilities.

Two exploratory and secondary aims have been also defined to sowing the seeds of future research, namely:

- a) The exploration of housing and employment relation with capabilities, analyzing the association between capabilities outputs and participant's housing and employment status.
- b) The cross-cultural translation and adaptation of the ACQ-CMH to the Italian and English languages, to obtain a multi-language measure of capabilities for further international comparative studies.

To accomplish the research aims, four sub-sequential studies have been designed.

- 1) *Study 1*. The first study regards the development of the measure in a collaborative perspective, which has been called the *Capabilities Questionnaire for Community Mental Health (CQ-CMH)*. Four steps are comprised, namely, the data collection, the data analysis, the item generation and the face validity. For the data collection, focus group sessions with 50 consumers of community mental health programs have been organized to identify their gains and goals in the programs. For the data analysis and item generation, a steering committee composed by two researchers and three consumers have been established to examine the data, generate a pool of items, and



organize them according to Nussbaum's list of capabilities. Finally, the face validity was checked with a group of 15 consumers to capture the measure comprehensiveness. The resulting CQ-CMH was composed of 104 items throughout the 10 theoretical dimensions of capabilities (Nussbaum, 2000). This study has been presented in the first published paper (Sacchetto et al., 2016).

- 2) *Study 2.* The second study consists in the assessment of the content validity, pursuing again collaborative procedures. A panel of eight participants, encompassing three consumers, three practitioners and two academic researchers, evaluated the relevance and adequacy of the instrument. Through this research phase, the measure has been reduced to a version composed of 98 items. This study is embedded in the second published paper (Sacchetto et al., 2018). The development process up to the 98-item version, has been also reported in the proceedings of the 3rd Congress of the Order of Portuguese Psychologists (Sacchetto, Ornelas & Calheiros, 2016 – Annex I).
- 3) *Study 3.* The third study explores the psychometric properties and validities of the 98-item version of the *Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH)*<sup>1</sup> with a sample of community mental health consumers (n=332), including the exploratory factor analysis (EFA); reliability comprising internal consistency and Test-Retest (T-RT) with a two-week interval between T1 and T2 testing (n = 33); convergent and divergent validity to check associations with other measures. By exploring and identifying latent variables through factor (PCA) analysis, Nussbaum's proposal of ten capabilities has been adapted to the specificity of the community mental health context. A version of 48 items and 6 factors has been obtained. This study is also reported in the second published paper (Sacchetto et al., 2018).
- 4) *Study 4.* The last study aims to confirm the factorial structure obtained in the previous phase with a new independent sample of community mental health consumers (n=225), in order to test its appropriateness. Therefore, a confirmatory factor analysis (CFA) has been developed, and psychometric qualities has been observed again, namely reliability

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<sup>1</sup> The name of the research instrument has been changed within the third study to *Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH)*, basing on literature review that underlines the conceptual difference between capabilities and functionings or achieved capabilities. Capabilities themselves are intended as freedoms or potential opportunities that when accomplished become functionings or achieved capabilities. Considering the aim of the research instrument here presented – i.e. analyze if consumers effectively achieve what they value - the term “Achieved Capabilities” has been considered more adequate.

(internal consistency and composite reliability); factor sensibility; discriminant validity of each factor; as well as divergent and convergent validity to confirm relations to other measures. The fourth study is described in the third submitted paper (Sacchetto, Ornelas & Calheiros, *Submitted*).

### **3.2. Research Context**

The present research context refers to the Portuguese community mental health system, specifically to the non-profit community structures in line with the national regulation of psychosocial rehabilitation and/or community mental health programs. This community-based response is the alternative to the large-scale psychiatric institutions, which still involve the majority of the national resources and consumers. Parallel to the de-institutionalization plan, in 2006, the Minister of Health in Portugal constituted a National Commission for the Renovation of Mental Health Services to develop a national plan to renew the mental health policy, called *Plano Nacional para a Saúde Mental 2007-2016* (PNSM) (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, 2006). This plan endorses the application of principles as self-determination, citizenship and participation in both community and organizational contexts, in line with community psychology values for mental health. Basing on these recommendations, a new law (DL 8/2010) was developed (later implemented through ordinance n° 68/2017) with guidelines for the national network of integrated care in the community context [*Rede Nacional de Cuidados Continuados Integrados* (RNCCI)]. This legal ordinance validates a recovery-oriented vision, enhancing the need to foster community engagement, consumers' rights and citizenship, personal goals and self-determination. However, programs and services are actually provided in multiple ways that foster or fail the real application of these principles. National findings show that some programs still follow institutional approaches, reflecting a profile of low-recovery orientation, while others present a high-recovery orientation, providing effective programs for social integration, as independent housing and supported employment (Jorge-Monteiro & Ornelas, 2016a).

The organizations that were involved in the present PhD work are part of the national community-based system of support with declared mission of recovery and integration. Their principal activities and services are provided in the following domains: housing, where the majority of these structure provide group homes and only a few adopt the independent housing model; professional training and employment, consisting principally in training courses

developed within the organizations and in protected jobs within social firms, whereas only some organizations follow the supported employment model; socio-occupational activities, such as artistic, cultural or physical, whereas some organizations develop also other activities oriented by psychotherapy and cognitive-behavioral models.

### **3.3. Research Procedures and Participants**

First, the research project was submitted to the Ethical Commission of the ISPA-University Institute (ISPA-IU), explaining the objective, methods, measures, procedures, and ethical commitments. Favorable agreement has been received to proceed with the research (Annex II).

For sampling, the Portuguese community mental health response has been analyzed, to capture a national picture of the existing structures, its legal orientation, objectives and principal activities. In this sense, two partnerships have been established: the first one with the Portuguese National Network of People with Experience of Mental Illness (*Rede Nacional de Pessoas com Experiência de Doença Mental*), to contact with people with mental health issues and experience of peer support and advocacy initiatives; the second one has been settled with the Portuguese Federation of Community Mental Health Organizations (CMHO), called *Federação Nacional de Entidades de Reabilitação de Doentes Mentais*<sup>2</sup>, in order to access to a list of national community mental health organizations that work under the same legal ordinance for community participation and integration. To reach potential participants, invitation letters have been sent to community mental health programs for each research phase, elucidating the research scope and procedures (Annex III). Participants of the focus group sessions, as well as respondents of the quantitative data collection have signed consent forms (Annex IV) to confirm their willingness in participating. Considering the study of content validity, invitation letters with detailed information about aims and procedures, have been sent to the panel of experts composed of consumers, service providers and scholars (Annex V).

Each step of the data collection throughout the diverse research phases, as well as the data analysis through participatory processes, have been organized and scheduled taking into account community mental health programs' availability and consumers' willingness.

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<sup>2</sup> <http://www.fnerdm.pt/>

Eligibility criteria for participation were the same at each research stage, namely: aged 18 years and older; reporting a mental health diagnoses; participating at the community mental health program for at least 2 months.

Several consumers were involved at different research stages, in order to pursue a collaborative approach. Regarding the study for the development of the measure (Study 1 – first phase), fifty consumers stemming from two different community mental health organizations in Lisbon have participated in the focus groups sessions. Participants were on average 42 years old ( $SD = 8.79$ ), the majority were male (70%) and involved in training courses or sport activities of the organizations (58%). Only 14% of them were studying, whereas the 28% were employed. For the face validity (Study 1 – fourth phase), fifteen consumers of one organization in Lisbon, volunteered for the task. The 20% were female, and almost half of participants were aged between 30 and 39 years (43%).

For the research phases that implied collaborative procedures for the analysis of the data, for the construction of the questionnaire (Study 1 – second and third phase), and for the assessment of the content validity (Study 2), members of the Portuguese National Network of People with Experience of Mental Illness (*Rede Nacional das Pessoas com Experiência de Doença Mental*) have been invited to participate.

While for the collection of quantitative data, namely for the exploratory and confirmatory study (Study 3 and 4), a total of 557 consumers of diverse community mental health organizations among the country have been involved. Table 3 reports details about the number and origin of consumers that participated at each research stage.

Table 3.

*Consumers that collaborated at the different research studies and phases.*

Research Study/Phase	Participants
Study 1 – Collaborative construction 1 <sup>st</sup> phase: Data collection through focus group	Consumers of <i>AEIPS - Associação para o Estudo e a Integração Psicossocial</i> (n=36) Consumers of <i>Recomeço - Associação para a Reabilitação e Integração Social Amadora/Sintra</i> (n=14)
2 <sup>nd</sup> and 3 <sup>rd</sup> phase: Data analysis and item generation through a steering committee	Members of <i>Rede Nacional de Pessoas com Experiência de Doença Mental</i> (n=3)

4 <sup>th</sup> phase: Face validity	Consumers of <i>AEIPS - Associação para o Estudo e a Integração Psicossocial</i> (n=15)
Study 2 - Content validity	Members of <i>Rede Nacional de Pessoas com Experiência de Doença Mental</i> (n=3)
Study 3 - Exploratory study (EFA)	Consumers of 15 diverse community mental health organizations among Portugal (n = 332)
Study 4 – Confirmatory study (CFA)	Consumers of 11 diverse community mental health organizations among Portugal (n = 225)

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Regarding the exploratory study, a sample of 332 consumers were involved, stemming from 15 community mental health programs. Geographically they were situated: seven in Lisbon, one in Sintra, one in Santarem, two in Setúbal, one in Oporto, one in Viseu district (Oliveira de Frades and São Pedro do Sul), one in Algarve region (cities of Loulé, Faro, Almandil), and one in the Autonomous Region of the Azores (Ponta Delgada). Respondents were between 19 and 80 years old ( $M = 44.14$ ,  $SD = 10.93$ ), mostly men (59%) and single (76%). About half of the sample had completed high school (46%), while the majority were unemployed/retired/receiving social benefit (83%). Only 48 participants were employed (11%) or working as volunteers (4%), although 62% of the whole sample declared to be willing to work. Concerning housing status, only one third was living independently (30%), while the majority was living with family (46%) and only 66% of participants said they had chosen their housing situation. Regarding the experience of mental illness, the most frequent self-reported diagnoses were schizophrenia (48%) and bipolar disorder (26%). Hospitalizations quite varied ( $M = 3.73$ ,  $SD = 4.7$ ), as the 78% of the respondents had been hospitalized at least once, up to a maximum of 40 times. Almost the half of the sample participated in the community mental health organizations in a range between 2 and 10 years (mode 2–5 years), whereas 26% of the sample were participating up to 11 years.

Concerning the confirmatory study, 225 consumers stemming from 11 community mental health organizations participated at this data collection. Nine of these organizations already participated in the previous gathering of quantitative data for exploratory purposes, although independent samples were pursued (consumers were allowed to participate at just one quantitative data collection). The two organizations that joined only this research stage were situated one in Penela municipality (Espinhal) and the other in Setubal municipality (Barreiro).

Participants presented quite similar characteristics than the sample of the previous study. They were aged between 18 and 76 years ( $M = 41.03$ ,  $SD = 12.43$ ) and 44% were female. Again, about half of the sample had completed high school (53%). The majority were single (78%) and unemployed/retired/receiving social benefit (78%), while only the 22% were working or committed to a trainee or volunteering. Almost half of the sample declared to be willing to work (55%). Regarding the housing situation, again, only the 30% lived independently, while almost half of the sample lived with the family (52%) and declared to be willing to move to another housing solution (45%). In terms of mental health issues, schizophrenia was the most reported diagnosis (45%), followed by bipolar disorder (24%). The number of hospitalizations varied also within this study sample, i.e. between one and 23 times at all ( $M = 3.54$ ,  $SD = 3.65$ ), where one third of participants (30%) were hospitalized once. Program utilization also significantly varied, precisely between 2 months and 30 years ( $M = 6.31$  years,  $SD = 6.44$  years).

### **3.4. Research Measures**

Basing on a literature review about community psychology contributions for community mental health (Bond et al., 2017; Nelson et al., 2014; Nelson et al., 2017; Townley et al., 2018), research instruments for the data collection of the different research stages have been identified. Specifically, for the focus group sessions of Study 1, a worksheet with open questions for the orientation of the group discussion has been elaborated (Annex VI), taking into account relevant dimensions for recovery and community integration (Davidson et al., 2006). Namely, consumers were asked to identify gains and goals they value in the following dimensions: employment, education, housing, community engagement and participation, social and familiar relations, physical and mental health.

For each of the quantitative data collection (Study 3 and 4), a specific protocol was elaborated (Annex VII), composed by a consent form, a sheet for participants' characterization, the ACQ-CMH and several measures for the assessment of the construct-related validity. One of the measures of the quantitative protocol required authorization for the use, which have been asked to the corresponding authors (Annex VIII). Specifically, to support the convergent validity of the ACQ-CMH, the following measures have been selected:

The *WHOQOL-Bref* is a quality of life scale developed by the World Health Organization and already validated in Portugal (Vaz Serra et al., 2006). It is composed by 26 items and four domains, namely Physical (seven items), Psychological (six items), Social

Relations (three items), and Environment (eight items). This instrument was selected in order to verify a positive association with the ACQ-CMH, since the capabilities approach was introduced as an alternative multidimensional framework for quality of life studies (Nussbaum & Sen, 1993).

The *Recovery Assessment Scale (RAS)*, was originally developed by Corrigan and colleagues (2004), and further validated in the Portuguese context (Jorge-Monteiro & Ornelas, 2016b). The 24-item scale has a 4-factor structure concerning the dimensions of Personal Goals and Hope (eleven items), Managing the Help Needs (three items), Supportive Interpersonal Relationships (four items) and Beyond Symptoms (six items). This scale was chosen expecting a positive association with the ACQ-CMH, considering the theoretical coherence within the concepts.

The *Empowerment Scale, (ES-P)*, in its Portuguese version (Jorge-Monteiro & Ornelas, 2014), which is a consumer-constructed measure (Rogers, Chamberlin, Ellison & Crean 1997). It consists of 25 items and a four-factor structure, including Self-esteem and Efficacy (nine items), Power-powerlessness Relations (seven items), Optimism and Control over the Future (three items), Righteous Anger (three items), and Community Activism and Autonomy (six items). As recovery, the empowerment concept is considered consistent with the capabilities framework. This measure was added only within the last confirmatory study (Study 4) to further support convergent validity and to check theoretical links evidenced by the results of the prior exploratory study.

To study the discriminant validity, a measure focusing on the opposite concept has been identified. In this sense the *K6* measure (Kessler et al., 2003) has been applied. This instrument is a nonspecific psychological distress scale composed by 6 items. Its brevity and accuracy in screening serious mental illness was intentionally chosen for the discriminant validity. The Portuguese translation was performed on behalf of the WHO Composite International Diagnostic Interview Advisory Committee by Yuan-Pang Wang and colleagues.

The ACQ-CMH developed within this PhD work, went through several analysis and refinements, basing on the results of the diverse research phases. Table 4 summarizes the different versions of the measure (see also Annexes IX – XI), obtained through the results of the different research studies. The ACQ-CMH asks about consumers capabilities achieved through the support of programs. In all versions, items start with a statement in a first-person

perspective: “Through the program support I was able to...”, in order to promote an individual critical reflection.

Table 4.

*ACQ-CMH different versions along the research studies.*

Study	Obtained version	Measure Structure	Rating scale
Study 1 Collaborative development; Face validity	CQ-SMC-104 (Sacchetto et al., 2016)	104 items and 10 dimensions	Proposal of 5-point Likert scale (from 5 = <i>totally agree</i> to 1 = <i>totally disagree</i> ), and an open-ended question about improvements
Study 2 Content validity	CQ-CMH-98 (Sacchetto et al., 2018)	98 items and 10 dimensions	4-point Likert scale (from 4 = <i>totally achieved</i> to 1 = <i>not achieved at all</i> ) with an option of not applicable (0 = <i>does not apply to my situation</i> ).
Study 3 T-RT and EFA	*ACQ-CMH-48 (Sacchetto et al., 2018)	48 items and 6 dimensions	4-point Likert scale (from 4 = <i>totally achieved</i> to 1 = <i>not achieved at all</i> )
Study 4 CFA	*AQ-CMH-43 (Sacchetto et al., Submitted)	43 items and 5 dimensions	4-point Likert scale (from 4 = <i>totally achieved</i> to 1 = <i>not achieved at all</i> )

\*The name of the measure has changed into Achieved Capabilities Questionnaire (Sacchetto et al., 2018)

### 3.5. Data Analysis

The data collected through focus group sessions were analyzed by a steering committee composed by 2 scholars and 3 consumers, intentionally invited as experts. Data were transcribed and analyzed first individually by each member of the committee to enhance the group discussion (Israel et al., 2005). Then, focus group responses were discussed and organized into categories and subcategories following a consensus strategy (Barker & Pistrang, 2005). Next, the most frequent and relevant data of each subcategory (i.e. 104 from a pool of 700 data) were chosen to compose the items of the questionnaire, converting into first-person statements. The 104 selected items were re-analyzed in light of Nussbaum capabilities list (a previous training session about the author framework was provided by the PhD candidate), in order to be organized throughout the 10 capabilities based on content matching and coherences.



Finally, 15 consumers volunteered for the face validity, to check the acceptability of the measure (Fitzpatrick et al., 1998), sharing their opinion about comprehensibility and adequacy of the measure.

Content validity was evaluated by a mixed panel of experts considering different backgrounds, namely consumer of the mental health system, service providers and academics. Each item was assessed in terms of relevance with a 5-point scale (1= *not relevant* to 5 = *very relevant*) and in terms of adequacy and phrasing clarity through qualitative observations. The Content Validity Index (CVI) was calculated (Rubio et al., 2003), and a final group meeting has discussed both quantitative and qualitative findings until a consensus on a final version has been achieved.

For the exploratory study, several analysis through SPSS version 22 were performed, namely: screening analysis to check normality, outliers; test-retest reliability through correlation and ANOVA between T1 and T2 applications; item-total correlation; parallel analysis to determine the number of components to retain; exploratory principal component analysis (PCA) with promax rotatin (correlation of components were above .20); examination of multiple loadings on items or low loadings (< .40) to decide on item elimination; internal consistency through Cronbach alpha and interitem correlations; convergent and discriminant validity observing Spearman bivariate correlations; associations between the ACQ-CMH obtained dimensions and independent variables, such as housing and employment profiles.

Within the last research study, in order to confirm the obtained six-factor and 48-item structure (hypothesized model), psychometric properties and validities were analyzed again, i.e.: screening analysis to observe normality, outliers, linearity, multicollinearity; confirmatory factor analysis with maximum likelihood estimation and the comparison of several commonly reported goodness-of-fit indices ( $\chi^2$ , CFI, TLI, RMSEA, ECVI, MECI); reliability calculating internal consistency through Cronbach alpha and interitem correlations, as well as composite reliability (CR); factors discriminant validity applying the average variance extracted (AVE); independent samples *t* test to explore professional and housing profiles in relation to ACQ-CMH dimensions; convergent and discriminant validity through Spearman bivariate correlations. For this research analysis both the SPSS, version 24, and the AMOS were applied.

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**EMPIRICAL SESSION**



**Article I – The Capabilities Questionnaire for the Community Mental Health  
Context (CQ-CMH):**

**A measure inspired by the capabilities approach and constructed through consumer–  
researcher collaboration**





The Capabilities Questionnaire for the Community Mental Health context (CQ-CMH): a measure inspired by the capabilities approach constructed through consumer-researcher collaboration

Beatrice Sacchetto<sup>1</sup>, Rita Aguiar <sup>2</sup>, Maria João Vargas-Moniz<sup>3</sup>, Maria Fátima Jorge-Monteiro<sup>1</sup>, Maria João Neves<sup>4</sup>, Adelaide Cruz<sup>4</sup>, António Coimbra<sup>4</sup>, & José Ornelas<sup>5</sup>

#### Author's Note

<sup>1</sup> PhD Candidates in Community Psychology at ISPA-IU - researchers of the project's academic team

<sup>2</sup> PhD Candidate in Community Psychology at ISPA-IU - person with lived experience, researcher of the project's academic team

<sup>3</sup> PhD, Assistant Professor at the ISPA-IU - researcher of the project's academic team

<sup>4</sup> Consumers and members of the Portuguese network of people with lived experience of mental illness – members of the Steering Committee of the project

<sup>5</sup> PhD, Associate Professor, Director of Community Psychology Department at ISPA-IU – principal investigator of the project

Corresponding author:

Beatrice Sacchetto

Address: Rua Jardim do Tabaco, 34, 1149-041, Lisboa, Portugal

Telephone: 00351 969223253

Email: [bsacchetto@ispa.pt](mailto:bsacchetto@ispa.pt)

The Capabilities Questionnaire for the Community Mental Health context (CQ-CMH): a measure inspired by the capabilities approach constructed through consumer-researcher collaboration

### **Abstract**

*Objective:* Traditionally the involvement of people with psychiatric disabilities in research and service evaluation has been rare, especially in the construction of outcome measures. This study documents a collaborative process with consumers from two Portuguese community mental health services in the construction of the Capabilities Questionnaire for the Community Mental Health context (CQ-CMH). The measure is inspired by Nussbaum's capabilities approach and aims at measuring consumers' capabilities supported by the community mental health services.

*Methods:* Focus groups with 50 consumers from two programs generated data about their gains from and goals for participation in the programs. A Steering Committee -comprised of three consumers and two researchers- analyzed data, generated a list of items, sorted them according to Nussbaum's list of capabilities, and developed a rating scale. To check face validity, the questionnaire was tested with 15 consumers.

*Results:* The collaborative process led to: the transformation of traditional research roles; the promotion of empowerment to participants; the ecological validity of the results; and a cultural adaptation of Nussbaum's list to the context under study. The resulting CQ-CMH is composed of 104 items organized by 10 capabilities, and one open-ended question about service improvements.

*Conclusions and Implications for Practice:* The capabilities approach and collaborative process undertaken both support the exercise of choice and control by people with psychiatric disabilities. The capabilities measure -constructed by consumers- may be used as an outcome measure in service evaluation. The questionnaire will undergo further testing of validity and psychometric qualities.

*Keywords:* capabilities approach; collaborative research; measure; consumers' perspective; community mental health services

## Introduction

Historically people with psychiatric disabilities suffered severe social segregation. Social exclusion limits individual opportunities grievously in many life domains, such as education, employment, relationships, and citizenship (Ornelas, Duarte & Jorge-Monteiro 2014). Lack of choice and self-determination has been reproduced at many levels of consumers' lives beyond participation in the community including involvement in the design and delivery of services to be received (Chamberlin, 2005) and collaboration in service evaluation and research activities (Jones, Harrison, Aguiar, & Munro, 2014; Springett & Wallerstein, 2008).

Accordingly, the present study proposes two means to overcome these challenges: the *capabilities approach* as a new framework that presents specific guidelines to orient community mental health services and to pursue a recovery mission, and a *collaborative approach* with the consumers, in order to guarantee access to choice and power of control to a historically oppressed population. Thus the twin goals of the present study are: (a) the development of a measure based on the capabilities framework; (b) the establishment of an empowering collaborative partnership between researchers and consumers.

### **The capabilities approach to inspire the mental health system**

The capabilities approach originated as an innovative approach to economic welfare and development through the work of Amartya Sen (Sen, 1980). Sen collaborated with the political philosopher Martha Nussbaum in the study of the quality of life (Nussbaum & Sen, 1993). In their framework, the focus shifted from income to *capabilities*, which are *substantive freedoms*, namely, what people can actually *do* and *be* given their own capacities, and the environmental opportunities to which they are exposed. In this sense, capabilities are a combination of both individual and social factors (Sen, 1999), underlining the need for supportive contexts. According to Nussbaum (2000), the capabilities approach represents a basic social minimum that all governments of all nations should implement. This perspective points to institutional and social responsibility for removing barriers, and creating favorable conditions for the promotion of individual capabilities. The capabilities framework is particularly relevant for groups who face challenges: people in a disadvantaged situation may need more institutional and social supports to achieve the same level of capabilities as more advantaged people (Shinn, 2014). Specific attention has been given to the population of people with a lived experience of mental health challenges (Davidson, Ridgway, Wieland, & O'Connell, 2009; Hopper, 2007;

Ware, Hopper, Tugenberg, Dickey, & Fisher, 2008). In the mental health field, capabilities theory is consistent with the values and principles of the empowerment and recovery models. The focus of the capabilities approach on people's agency converges with the empowerment values of decision-making power and choice (Rappaport, 1985). For empowerment to occur, consumers need to be active decision makers by choosing which activities to pursue, instead of receiving pre-established programs passively (Sen, 1999). The opportunity for consumers to define and lead their recovery processes makes the substantive difference for system change, because it implies a transformation of the professional role. Mental health practitioners should first identify consumers' interests and choices, and consequently facilitate access to a wide range of socially relevant roles (Hopper, 2007). In fact, recovery is best promoted in natural environments that provide people opportunities and resources to carry out significant activities (Davidson et al., 2009).

Whereas Sen (1999) focuses on freedom and *agency*, Nussbaum (2000) outlines a normative list of human capabilities, including economic, political, social and civic liberties owed to every citizen in every country. The dimensions proposed in Nussbaum's framework are formulated at a high abstract level, so that every community has the liberty to adapt them to the local context: "each nation must and should describe the capabilities it pursues more concretely, using their own history and tradition as a guide" (Nussbaum, 2011, p.29).

The capability approach has already been applied to elaborate measurements in areas such as health economics and public health (Anand et al., 2009; Lorgelly, Lawson, Fenwick, & Briggs, 2010), also in the mental health field an operationalization of the capability approach for outcomes measurement in clinical studies was introduced (Simon et al., 2013).

The present study proposes another measure grounded on a collaborative process between researchers and consumers: each phase of the instrument development was pursued with consumers' participation.

### **The collaborative approach to enhance consumers' agency**

The adoption of a collaborative approach is a key principle of community-based research, because it listens to often-oppressed voices (Rappaport, 1985), and promotes social change (Israel, Eng, Schulz, & Parker, 2005). A collaborative effort is an empowering process that affects community members – by respecting and valuing their experiential knowledge – as well as the research itself, by producing valid knowledge that attends to community issues

(Christhens & Perkins, 2008). In the health field, consumer participation has been considered a vehicle to reduce consumer dependency on health professionals (Minkler & Wallerstein, 2008). In mental health, consumers have historically endured oppression and dependency on the system. Participation is a fundamental means to emancipate and empower consumers: it represents an opportunity for consumers to take or share control over the system instead of receiving professional interventions passively (Lord & Dufort, 1996; Jones et al., 2014). A central challenge in a collaborative approach is the power imbalance between researchers and community members (Carrick, Mitchell, & Lloyd, 2001; Nelson, Lord, & Ochocka 2001). Academic researchers perpetuate the false myth that community members have no resources and abilities useful for research development. Professionals often resist collaboration with consumers, due to the fear of losing their privilege and position as experts, which enables them to maintain the control of the research agenda (Ochocka, Janzen, & Nelson, 2002). Further, disparities in professional and scholarly background, or in time perspective, can lead to misunderstanding, and to a climate of mistrust that hinders collaborative effort (Riger, 2001). In order to overcome all the existing gaps between groups, a “bridge-building process” needs to be established (Sullivan & Kelly, 2001, p.4), where both academic and consumers contribute with their mastery and knowledge. As Boothroyd et al. stated (2004), the articulation of *scientific* and *significance assessment* produces knowledge with relevant individual, social, and political impacts. Moreover, consumers often manifest interest and willingness to contribute to research activities, because of dissatisfaction and frustration with current clinical and academic research, or a desire to see advances in the mental health system (Telford & Faulkner, 2004).

Beyond participation in research activities, consumers have the right to be involved in service delivery and evaluation (Chamberlin, 2005; Springett & Wallerstein, 2008). Nevertheless, recent studies report that even the definition of service outcomes is often not relevant to consumers and quite different from what they expect from a mental health service (Thornicroft & Tansella, 2010; Rose, 2001). Moreover, professionals or university researchers have constructed the majority of the existing outcome measures without including consumers’ perspectives (Rose et al., 2011). Thornicroft and Tansella (2010) underline the importance of a *user-valued measure*, in other words, a measure “that reflects the values and experiences of a majority of consumers” (p.4), especially in areas of satisfaction, quality of life and service outcome.

Following these arguments, the present study describes a collaborative approach to construct the capabilities measure proposed here.

## Methods

### Context

The academic team is composed by 5 researchers in community psychology from the Portuguese ISPA-IU University (*ISPA-Instituto Universitário*), one of them with lived experience of mental health challenges. To obtain variability in data about consumers' experiences, two community mental health services in Lisbon were identified: the Association for the Study and Psychosocial Integration (AEIPS), a private and non-profit organization, with the mission of recovery and community integration (Ornelas et al., 2014); and the Association for the Rehabilitation and Social Integration (RECOMEÇO), a community program developed by the psychiatry department of a general hospital, with the aim of psychosocial rehabilitation and socio-occupational integration.

### Study design

To pursue the goal of constructing the questionnaire based on consumers' perspectives, the academic team defined a qualitative and collaborative research procedure, composed of the following phases: (1) data collection through focus groups about consumers' gains and goals; (2) data analysis, item and rating scale development by a Steering Committee purposefully constituted of two researchers of the academic team and three consumers; (3) review and organization of the data based on Nussbaum's capabilities list by the same Steering Committee; (4) examination of face validity with the help of 15 consumer volunteers.

Further studies will make use of quantitative methods to produce a well-established measure suitable for community mental health services evaluation.

### Procedures

#### *First Phase: data collection*

The aim of the first phase was to gather information about consumers' goals and gains in the community mental health service they were attending. Consumers' aims were considered a key dimension reflecting achievable capabilities, which were later translated into *functionings* (achieved or functional capabilities), in order to assess whether the consumers have access to valued activities and roles.

Focus group sessions were conducted, in order to empower participants' voice, and to promote critical reflection (Denzin & Lincoln, 2005). The criteria for consumers' participation were: at least three months of service utilization and a psychiatric diagnosis. 50 volunteers participated, 36 from the AEIPS organization, and 14 from the RECOMEÇO service. After signing consent forms, they completed brief questionnaires covering demographic and organizational information. The majority (70%) of participants were male, with an average age of 42 years ( $SD=8.79$ ). At time of data collection, 14% were studying, 28% were working and the remaining 58% were involved in other activities at the two programs (e.g. sport activities, courses of languages or computers). Each focus group received a worksheet to orient their discussion based on the dimensions identified earlier as being important to recovery and community integration (Nelson et al., 2014)<sup>3</sup>. Groups were composed of five consumers on average and one facilitator to foster participants' involvement (Becker, Israel, & Allen, 2005), and were heterogeneous with respect to the length of time consumers had used the services so that people with a long experience could debate ideas with consumers who had joined more recently. Each group selected a note taker with the task of recording the group's idea (Krueger, 2006). First, participants discussed the gains they achieved through participation in the programs. Then, they discussed the goals they would like to pursue with the programs' supports. Overall, a total of eleven focus groups were held: eight in the AEIPS organization, and three in the RECOMEÇO service. The academic team collected eleven worksheets with the notes of the groups' discussions.

### ***Second Phase: consumer-oriented data analysis, item and rating scale development***

A specific Steering Committee (SC) for the data analysis task has been established, composed by two members of the academic team and three consumers (two females and one male) purposefully invited to join the panel as experts on their own experiences (van Draanen et al., 2013). The three consumers are leaders of the Portuguese National Network of People with Experience of Mental Illness (*Rede Nacional das Pessoas com Experiência de Doença Mental*) and actively engage in campaigns for peer support, and representation of peers in conferences/meetings in the area of mental health.

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<sup>3</sup> Six questions for the gains discussion, namely "What kind of gains did you obtain in: education?; employment?; relationships, e.g. with family/friends/other community members?; housing?; participation in service delivery and assessment?; physical health and wellness?", and six for the goals discussion regarding the same dimensions "Which goals do you identify in education?; ..." In order to identify additional underestimated research topics (see Kennedy, 2003), an open space was added "Any gains and goals in other areas?"

The focus group data were transcribed and distributed to all the committee members for a first individual analysis to maximize the group discussion (Israel et al., 2005). In the first meeting, the SC designed three steps for the data analysis: the categorization of the data; the selection of the most significant content; the development of a list of items and a rating scale. For the first task, the data were discussed and organized into categories and subcategories, depending on the contents of the reported gains and goals. Following Barker and Pistrang's (2005) consensus strategy to check the credibility of the data interpretation, the SC discussed the categorization of each group's responses, until an agreement was achieved. The group discussion served also to clarify the significance of the data, and to collapse very similar statements without losing meaning (Becker et al., 2005). In fact, often, testimonies about gains and goals were repeated among different groups. In these cases, the groups' responses were integrated in a unique citation, and the frequency was registered. The same categorizing procedure was pursued for both gains and goals data.

Table 1. Examples of categorization process of focus groups data.

*“What kind of gains did you obtain in physical health and wellness?”*

CATEGORY	SUBCATEGORY	GROUPS' RESPONSES	N
Health	Physical issues	G 1,2,3,5,7,8,10,11: “To practice more physical activity.”	8
	Mental issues	G 1,5, 6, 9, 10: “Reduce worries about mental illness.”	5

*“Which goals do you identify in employment?”*

CATEGORY	SUBCATEGORY	GROUPS' RESPONSES	N
Working	Achievement of new skills	G 2,4,6,9: “To accomplish my commitments.”	4
	Get a salary	G1,3,4,5,6,7,8,10,11: “To become financially more independent.”	9

Around 700 responses were categorized by the SC, from which 104 (corresponding to the most frequent of each subcategory) were chosen to constitute the items of the questionnaire. Then, the selected comments were transformed into critical reflections about individual opportunities provided by the service (e.g. “Participating in this mental health service allowed me to practice more physical activity”; “Participating in this mental health service allowed me to reduce worries about mental illness”). Finally, the SC debated about options of rating scales, and decided to chose a 5-point Likert scale ( $1 = \textit{totally disagree}$  and  $5 = \textit{totally agree}$ ) to give



consumers a range of responses about accomplished capabilities.

The committee met 20 times to complete these tasks.

### ***Third Phase: the capabilities-oriented data review***

The goal of the third stage was to develop a capabilities-oriented measure, inspired by Nussbaum capabilities list (see Nussbaum, 2000, pp.78-80). Therefore, the SC attended a training session: a researcher from the academic team presented the capabilities approach, and Nussbaum list. The list was then translated into Portuguese and used as the interpretive framework (Barker & Pistrang, 2005) to logically structure the items: each of the 104 items previously elaborated was fitted in the most coherent capability. The matching of consumers' testimonies collected through the focus groups, and Nussbaum's list, took twelve meetings. A list of capabilities with specific and adapted definitions resulted from the blending of consumers' testimonies and Nussbaum's original definitions (see Appendix).

Finally, the consumers that participated in the SC were asked to write down how they felt during the working sessions, namely how they experienced the collaborative relationship.

### ***Fourth phase: face validity***

To check the acceptability of the measure (Fitzpatrick, Davey, Buxton, & Jones, 1998), the resulting questionnaire was tested with a group of consumers of the AEIPS organization (N=15), who volunteered for the task. Participants signed consent forms and completed a brief demographic questionnaire. The group was 20% female with 43% between 30 and 39 years of age with the remainder over 40. The majority (58%) had used the service for more than ten years with the rest split between 3 months and 1 year (17%), 1 and 3 years (17%), and 4 and 10 years (8%). Consumers were invited to share with the group their opinion about the measure, namely about the comprehension of the items, the language used, and the importance of the questions addressed.

## **Results**

### **The CQ-CMH**

The questionnaire consisted of 104 items ordered by the 10 capabilities and measured

on a 5-point Likert scale, which represents the theoretical structure that will be tested in future studies through quantitative methods. A last open-ended question about how community mental health services could better promote consumers' capabilities was added to give consumers the opportunity to express their perspective. Items were developed from focus group data about consumers' goals and gains. In this sense, the experiences and values of the participants served to elaborate the indicators of capabilities.

The CQ-CMH pretends to contribute to the evaluation of community mental health services outcomes, measuring whether consumers are achieving functional capabilities. The achievement of capabilities can be seen as an institutional outcome as well as an individual result, because it reflects the professional endeavor in improving consumers' quality of life. Therefore, the results obtained through a capabilities measure may orient the service delivery, pointing at the strengths and weakness of the services, namely which domains of consumers' life should be provided more support.

### **Transformation of traditional research roles**

People with lived experience of mental health challenges have the right of being formally hired as research workers (Delman, 2012; Jones et al., 2014). Therefore, the academic team of the ISPA-IU included a person with lived experience that was hired with a research contract. Promoting the access of employment opportunities in the research field allows the achievement of social justice and equitable status (Ochoka et al., 2002).

For the data analysis task, the SC was composed of two researchers of the academic team and three consumers. That way, the population to whom the research is intended, represented the majority of the working group. These consumers were invited purposefully (van Draanen et al., 2013) due to their long experience as consumers/survivors in the mental health system, i.e. valuing their personal experience as a unique source of information.

The SC was an effective group, because all the partners contribute with their skills and competencies to pursue the research goals (Becker et al., 2005). Traditional research roles were changed into more equal relationships. When consumers of the SC were asked how they felt during the collaborative working, one said:

*“Our relationship was one of equal importance and capacity relating to the construction of the questionnaire [...] the decisions weren't taken only by the researchers [...] the researchers that worked with us*

*heard and accepted many of our suggestions.”*

Moreover, the meetings of the SC were always scheduled accommodating consumers' needs, for instance, organizing break during the intensive work of data analysis and review. The communication was clear, open and adapted to consumers' language, creating a comfortable and trusting climate as well as supportive relationships within the working group (Israel et al., 2005; Delman, 2012).

### **Empowerment promotion**

Participation, choice and power-sharing processes are potential means to promote empowerment (Lord & Dufort, 1996; Ochoka et al., 2002). One consumer of the SC reflected:

*“I felt relaxed and that no one was bossing me around [...] I felt that my role was significant because my opinions were taken into account”*

These testimonies suggest that professionals were willing to share power and control. Beyond this, formal opportunities of learning and discussion were provided (Ochocka et al., 2002): a formal training session about the capabilities theory was developed, presenting a new perspective for assessing the quality of life; the overall 32 meetings of the SC allowed the exchange of views and skills, and a process of mutual-influence (Rappaport, 1990). Moreover, the collaborative work fostered the strengthening of individual abilities that were not obvious even to participants, and which may be useful in the future (Trickett & Espino, 2004). As one participant of the SC put it:

*“I learned to work in a team, and felt empowered.”*

### **Ecological validity**

The collaborative approach improves the ecological validity of the produced knowledge (Christens & Perkins, 2008; Trickett & Espino, 2004). Consumers have offered point of views and took initiatives that had a positive impact on the development of the research. For instance, consumers of the SC often understood better than researchers what the focus group discussions meant, e.g. about challenges resulting from the experiences of mental health problems and social stigma, or about services they need for support. Their perspective permitted an accurate interpretation of the data. A consumer member of the SC mentioned that:

*“There was a lot about the questionnaire that needed to be improved or replaced in order to make it intelligible and we always had a word in that matter [...] the opinion of people with mental illness experience often prevailed. What I mean is that the questionnaire was constructed based on the perspective of the people with mental illness experience.”*

Consumers’ opinion prevailed also in the development of the items, and in the language use. This led to a positive result in the face validity: consumers that participated in the task (N=15) confirmed the familiarity with the language used, and the relevance of the addressed issues. They said also that the questionnaire was understandable and easy to fill out, although too extensive.

### **Cultural adaptation of Nussbaum’s list**

While creating a capabilities oriented instrument we are also contributing to the application and measurement of the capabilities approach. Nussbaum’s capabilities list was reformulated based on consumers’ testimonies and perspectives: the SC developed a proposal of 10 adapted capabilities with specific elements (see Appendix). In this sense, the constructed capabilities list represents what consumers would like to *do* and to *be* in these life domains, namely, valued activities and roles that they would like to enact through the service support. To give an example, we focus on Nussbaum’s health capability. To better adjust this capability to the mental health context, the SC chose items –previously elaborated based on focus group results- about both mental and physical health issues, like reducing worries about mental health challenges, and having healthy habits (such as physical activity and healthy eating). Aware that the healthy behaviors are an important concern for people with psychiatric disabilities, the SC defined the health capability as a combination of states and activities to pursue physical and mental wellness.

### **Conclusion and Implications for Practice**

The present study proposes a questionnaire that aims to contribute to the evaluation of the outcomes of community mental health services. The CQ-CMH presents two innovative elements. First, the measure is inspired by the capabilities approach which focus consumers’ freedom of choice to *be* and to *do* what they value (Nussbaum & Sen, 1993). Nussbaum’s list

suggests specific dimension of individual quality of life that should be guaranteed by institutional contexts (Nussbaum, 2000). The capabilities approach offers useful criteria to promote individual capabilities and to evaluate whether program services are recovery oriented (Davidson et al., 2009; Hopper, 2007; O’Connell & Davidson, 2010). Finally, “the capabilities approach focuses on ends: what a transformed system should secure to its participants” (Shinn, 2014, p.83). In this sense, the CQ-CMH is a proposal of what the community mental health services should provide to its consumers. In addition, the present study relied on a qualitative and collaborative process to develop the instrument. Accordingly, the second innovative element is the collaborative approach as a means to promote consumers’ choice and agency. By collaborating with consumers of the SC, the academic team pursued a consumer-oriented data analysis (Rose, 2001). The items of the questionnaire were generated valuing the perspective of the people who have the understanding of their situation (Thorncroft & Tansella, 2010). Consumer proficiency needs to be reevaluated as an exclusive source of information about facing mental health challenges, and participating in the mental health system (Carrick et al., 2001).

The collaborative approach promotes dimensions close to many capabilities as indicated by Nussbaum (2000), like the *practical reason*, and the *control over the environment*. To pursue the capabilities mission mental health professionals need to overcome power imbalances and impaired states (Telford & Faulkner, 2004) through the collaboration with consumers. Joining the collaborative and capabilities languages, we may affirm that the active participation of consumers is a vehicle to foster individual agency and freedom.

Future studies will analyze psychometric qualities (e.g. reliability, factorial structure) and validities of the measure (e.g. content, construct validity).



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Appendix. The capabilities list constructed by the Steering Committee composed by 3 consumers and 2 researchers.

Capability*	Definition
1. Life	Be hopeful to live a life of normal length; have good life conditions.
2. Health <b>(Physical and Mental)</b>	Be aware about the physical and mental conditions; make necessary medical examinations autonomously and have control over the health care, including medication; be active in the process of recovery; have a healthy and balanced diet; not engage in risk behaviors.
3. Bodily Integrity	Have no fear of being a victim of violence or sexual abuse; feel safe in public spaces and transport; feel safe in home; feel free to experience sexuality.
4. Senses, Imagination and Thought	Use the senses, imagination, and thoughts constructively and productively in one's own life; increase the education; develop the intellectual capacity; be informed, creative; cultivate one's own interests.
5. Emotions, <b>Feelings, and affective Relationships</b>	Have self-confidence and self-esteem; be empathetic and optimistic; be hopeful about the future; improve relationships with family and friends; be autonomous in relation to mental health services and professionals.
6. Practical Reason, <b>Critical Reflection</b>	Think critically about life situations; be able to make decisions and to seek solutions and resources to achieve personal goals; be independent in everyday tasks; make plans for the future; have decision making power over life; have more autonomy in the management of the medication.
7. Affiliation, <b>Social and Community Interactions</b>	Have respect and regard for oneself and for others; non-discrimination and stigmatization as basis to create and enrich social and community relations; meet other people without serious mental illness and establish relations with them; have feelings of belonging to the community.
8. Other Species	Respect and enjoy the natural environment; take care of other species.
9. Play <b>and Leisure</b>	Have fun with colleagues and friends; enjoy recreational activities.
10. Control over one's environment-material, <b>resources, political and civic</b>	Have control over own resources, equal opportunities and rights in the area of education, housing, employment (have opportunities for employment in the regular and competitive labor market); exercise civil and political rights; participate at the organizational level (in mental health services); participate in issues related with mental health policy; be an active citizen.

\* The differences comparing to Nussbaum original list are in bold text



**Article II – Adaptation of Nussbaum's Capabilities Framework to Community  
Mental Health: A Consumer-Based Capabilities Measure**



Adaptation of Nussbaum's capabilities framework to community mental health:

A consumer-based capabilities measure

Sacchetto, B.<sup>1</sup>, Ornelas, J.<sup>1</sup>, Calheiros, M. M.<sup>3</sup>, Shinn, M.<sup>4</sup>

Author's Notes:

<sup>1</sup>PhD Candidate in Community Psychology at ISPA – Instituto Universitário (ISPA-IU),  
Lisbon Portugal

<sup>2</sup>PhD, Associate Professor, Department of Community Psychology at ISPA – Instituto  
Universitário (ISPA-IU), Lisbon Portugal

<sup>3</sup>PhD, CIS-IUL Research Center, ISCTE-Instituto Universitário de Lisboa, Portugal; Centro  
de Investigação em Ciência Psicológica, Faculdade de Psicologia, Universidade de Lisboa,  
Portugal.

<sup>4</sup>PhD, Department of Human and Organizational Development, Peabody College, Vanderbilt  
University, Nashville, TN, USA

Corresponding author:

Beatrice Sacchetto

Address: Rua Jardim do Tabaco, 34, 1149-041, Lisboa, Portugal

Telephone: 00351 969223253

Email: [bsacchetto@ispa.pt](mailto:bsacchetto@ispa.pt)

### **Abstract**

The capabilities approach provides a rich evaluative framework to guide transformative change in the community mental health system. This paper reports the content and construct validity and psychometric properties of a contextualized measure of the extent to which mental health programs foster achieved capabilities. The Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH), adapted from Nussbaum's capabilities framework, was developed previously with consumer collaboration. Content validity was assessed through a collaborative process, involving a panel of 8 consumers, staff members and senior researchers. The resulting shorter version (ACQ-CMH-98) was completed by 332 community mental health consumers sampled throughout Portugal. Factor (PCA) analysis, internal consistency reliability, and test-retest reliability over two weeks (N=33) showed good psychometric properties. The resulting 6-factor structure with 48 items explains 48.88% of the total variance (KMO=0.89; Bartlett  $p=.00$ ). Internal consistency of the obtained dimensions ranges from .91 to .76. Associations of the measure with recovery, quality of life and psychological distress scales add further evidence of construct validity.

The adaptation of Nussbaum's framework stressed specific components that may enhance understanding and change within the community mental health system.

Key-words: contextualized capabilities; Nussbaum list; adaptation; community mental health; measure; psychometric properties



## **Introduction**

The capabilities approach has received much attention among philosophers, economists, and social scientists concerned with human development and the social, political and economic conditions that promote quality of life and social justice (e.g. Deneulin & McGregor, 2010; Nussbaum & Sen, 1993; Robeyns, 2005; Sen, 1982). In mental health, the capabilities framework offers a way to orient social programs towards a system change, restoring consumers' agency, social roles, and community integration (Davidson, Ridgway, Wieland, & O'Connell, 2009; Ware, Hopper, Tugenberg, Dickey, & Fisher, 2008). The current paper examines the validity and psychometric properties of a measure of the extent to which mental health programs foster consumers' capabilities.

### **Capabilities Framework and Community Mental Health**

The innovative focus of the capabilities approach to quality of life and well-being, as proposed by the pioneer Amartya Sen (1982), is on the exercise of freedom rather than on the traditional utilitarianism behind welfare economics. Capabilities are defined as freedoms to be and to do, or the real opportunities to achieve what one values (Sen, 2004). When chosen and enacted, these beings and doings become valuable *functionings* that make a life worth living.

The concept of capability does not refer to an intra-individual dimension; rather it underlines the relevance of context. Indeed capabilities are defined as *combined capabilities*, resulting from personal abilities and external circumstances including social and political arrangements (Nussbaum, 2011). Another crucial element of the theory is the concept of agency, stressing the individual's participation in society, as a full member engaged in economic, social and political arenas. Individuals are the principal actors of their lives (Sen, 2004).

In the capabilities framework, human wellbeing and quality of life are situated at the core of social processes. Social factors have a crucial impact since individuals' positions and roles influence their access to opportunities and means to exercise freedom (Smith & Seward, 2009). Thus, people's settings may facilitate and promote individual capabilities, or on the contrary, may negatively interfere in the process of capabilities development. This last case is particularly problematic for groups that already suffer a disadvantage, like poverty, or physical or psychiatric disabilities, and who have historically been oppressed and segregated (Benbow, Rudnick, Forchuck, & Edwards, 2014; Burchardt, 2004). For these disadvantaged groups, the

promotion of agency and freedom may require contextual aids (Shinn, 2015). Social structures that aim to respond to vulnerable populations should therefore provide specific supports to enable their capabilities.

The capabilities approach presents continuity with the principles and goals of recovery and empowerment in community mental health (Davidson et al., 2009; Hopper, 2007). Self-determination, which recalls the freedom to choose, is the cornerstone of recovery; defining and leading one's life is a critical counterpoint to oppressive systems that have dispossessed consumers' rights (Chamberlin, 1978). Social justice and freedom sustain the idea of human diversity, as recovery rejects a standard notion of illness versus health (Davidson et al., 2009). Similarly, the focus of empowerment theory on individuals' power and control (Zimmerman, 2000) corresponds to Sen's concept of individual agency (Sen, 2004). As in the capabilities approach, the empowerment account stresses the role of context: relational environments are an opportunity to grow and learn via mutual influences and community alliances (Christens, 2012); the setting itself may be a resource for empowerment. Both empowerment and capability theories help community psychologists to identify setting features that promote individual potential (Shinn, 2015) and foster empowerment (Jorge-Monteiro, Aguiar, Sacchetto, Vargas-Moniz & Ornelas, 2014; Maton, 2008).

The capabilities approach has been adopted as a rich evaluative framework to assess social care and public health interventions (Lorgelly, Lorimer, Fenwick, Briggs & Anand, 2015). Wallcraft and Hopper (2015) proposed a social model of mental health, with a focus on deficits in the system, and not in individuals with a focus on deficits in the system, and not in individuals (Shinn, 2015). The capabilities perspective suggests both a deep analysis of the system, its policies and structures to identify what contextual barriers persist, as well as a reconsideration of consumers' role in service planning, delivery and evaluation (Wallcraft & Hopper, 2015). Here, stigma and social exclusion can be overcome with opportunities for integration, interpersonal connectedness, citizenship, and engagement in valued social roles (Ware et al., 2008). Likewise, consumer dependency and professional resistance to sharing power can be replaced with people's agency and control within the mental health system (Sacchetto et al., 2016).

### **Nussbaum's Capabilities List**

Within the capabilities literature, there is no consensus on whether and how capabilities should

be listed (e.g. Sen, 2004). Some theorists enumerate capabilities to provide concrete dimensions to be studied (e.g. Alkire, 2002; Nussbaum, 2000). The philosopher Martha Nussbaum claims a broad cross-cultural consensus for a list of capabilities that represents a social minimum of what a fully and worthy human life requires. However, she recommends adaptation to specific contexts and cultures (Nussbaum, 2011). Her list includes ten domains: *life; health; bodily integrity; senses, imagination and thoughts; emotions; practical reason; affiliation; other species; play; control over one's environment* (see Nussbaum, 2000, p. 79-80). These capabilities include primary goods, such as material and cultural requirements, as well as more complex capabilities like the exercise of control, practical reason and social relations (Hopper, 2007).

Elsewhere, the parallels between Nussbaum's capabilities list (2000) and community psychology values have been discussed; for instance *senses, imagination and thought*, along with *emotions* and *affiliation* call up ideas of social capital and social support, and *practical reason* and *political control* recall the individual level of empowerment (Shinn, 2015).

Many of Nussbaum's dimensions (2000) are particularly important for people with mental health challenges. Consumers often face social stigma that hinders community relations, and social integration is central to recovery (Hopper, 2007). Therefore, Nussbaum's *affiliation* ("Being able to live with and towards others, to recognize and show concern for other human beings, to engage in various forms of social interaction; [...] Having the social bases of self-respect and non-humiliation; [...] protections against discrimination"; Nussbaum, 2000, p.80) is a core issue in community mental health.

Nussbaum's (2000) *control over one's environment* ("Being able to participate effectively in political choices that govern one's life; having the right to political participation, protections of free speech and association [...]"; p. 80) provides a crucial contrast to the belief that people with mental illnesses should wait for "some mythical later time" in the recovery process to get their lives back (Davidson et al. 2009, p. 41). Community psychologists argue that there are no material, social, or political preconditions for being citizens with civil and political rights (Nelson, Kloos & Ornelas, 2017).

Other dimensions, such as *life* and *health*, are strongly pertinent in that mental health consumers face a reduction of 25 years in life expectancy due to medical issues, nutritional choices, sedentary behaviors and medical side effects (Newcomer, 2007). With *bodily integrity*, *other species*, and *play*, Nussbaum (2000) introduces feeling of security, relation with the nature

and opportunities to enjoy life that may be relevant in community mental health.

Nussbaum's list of capabilities (2000) thus seems an appropriate framework for considering the extent to which mental health programs help consumers to achieve a life worth living. However, her dimensions were developed from a philosophical ground, and represent a starting point that requires context-oriented specifications (Nussbaum, 2011). In this paper, we undertake a process of adaptation and further validation to produce contextualized definitions of capabilities, which may contribute to orienting a transformative change in community mental health.

### **Capabilities Application and Measurement**

The multidimensionality of the capabilities approach creates challenges for measurement. Further, the capabilities framework entails several theoretical elements (Robeyns, 2005) to choose among depending on the research aim and context (Verkerk, Busschbach & Karssing, 2001). For instance, studies may focus on the possibilities that one could achieve (i.e., capabilities themselves) or on achieved capabilities (i.e., functionings; Alkire, 2002). Sen (2004) focuses on the broad concept of capability as opportunity, however he states that it is easier to measure functionings that are carried out to assess well-being. Indeed, quality of life consists in achieving doings and beings in life domains that one values (Davidson et al., 2009). Other choices include focusing on perceived versus objective capabilities/functionings, and on self-reported versus professional-reported measures (Simon, Anand, Gray, Rugkasa & Yeeles, 2013). Self-evaluation through the use of self-reported measures reduces dependency on professionals and promotes users' empowerment (Minkler & Wallerstein, 2008).

Some argue that any application of capabilities should start with a definition of valued functionings (Hopper, 2007) and qualitative research to identify which functionings to include (Verkerk et al., 2001). Collaboration with the target population ensures that the defined functionings reflect capabilities that people value and would like to achieve (Sacchetto et al., 2016). Thus Nussbaum's general list (2000) serves as a guide for adaptation of "contextualized capabilities," or "the set of capabilities [that] are determined by the relevant subjects/target population" (Smith & Seward, 2009, p.230).

Past research on operationalizing the capabilities framework falls short in several ways. Development of capabilities measures along with research on mental health outcomes more

generally has lacked consumer involvement (Kinghorn, Robinson, & Smith, 2014; Telford & Faulkner, 2004). Further, few empirical studies of capabilities measures report psychometric properties (Hofmann, Schori, & Abel, 2013; Simon et al., 2013). Anand and colleagues (2009) worked on an operationalization of Nussbaum capabilities list using a large scale survey. Other applications include an 18-item capability index (OCAP-18) for the evaluation of public health interventions in Scotland (Lorgelly, Lorimer, Fenwick, Briggs & Anand, 2015); and an adaptation for outcome measurement in mental health in people subject to Community Treatment Orders in England, producing the OxCAP-MH (Simon et al., 2013). However this latter adaptation was performed by a focus group composed exclusively of professionals and focuses on deficits rather than achievements. Content validity and feasibility were studied with a pilot test within the target population.

All of these applications of Nussbaum's framework (2000) used pre-established questions and proposed a unifactorial structure, which is in tension with the multidimensionality nature of the capabilities approach. Nussbaum (2011) is explicit that capabilities cannot be traded off, one for another.

The current research provides further validation of a multi-dimensional self-report measure of achieved capabilities (functionings), named the Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH). The measure was initially developed collaboratively with consumers of mental health services (Sacchetto et al., 2016). Focus groups with 50 consumers generated data that were analyzed by three consumers and two researchers in order to generate a list of items, and to sort them according to Nussbaum capabilities list (2000). The measure assesses capabilities attained with the support of programs, and thus can be used to evaluate the extent to which mental health programs foster consumer's gains in achieving capabilities. Mental health programs are embedded in larger social contexts that also affect whether people can attain valued functioning. We focus on measuring program contributions to capabilities as a critical tool for transformative change in the mental health system, by reorienting programs to assist consumers to attain doings and beings that they value.

### **Research Context – Community Mental Health in Portugal**

Although substantial progress on deinstitutionalization has been made over the last 30 years, the Portuguese mental health system is still based on two pillars: the large-scale psychiatric institutions, which hold the majority of the resources and consumers, and the

community-based structures, mostly non-profit organizations around the country. This second axis of social response, under study here, is particularly committed to deinstitutionalization, recovery and community integration.

In 2006, the Minister of Health in Portugal constituted a National Commission for the Renovation of Mental Health Services in order to develop an Action Plan (2007-2016). Recovery and self-determination, community participation, citizenship and consumer collaboration in service planning and delivery were named as core values. Based on these ideas, a new law was proposed in 2010 (Decree-Law n° 8/2010)<sup>4</sup> - but only recently implemented through ordinance n° 68/2017 - to define guiding principles for community mental health, including "promoting an independent life and an active role in the community", "respect for civic, political, economic, social and cultural rights for the effective exercise of full citizenship", and "strengthening the skills and capabilities of persons with psychosocial incapacity" (DL 8/2010, p. 258).

However, recent national studies affirm that part of the community mental health programs still follow institutional approaches and standard interventions, maintaining the segregation and social exclusion of people with mental health problems, and hindering valued social roles (Jorge-Monteiro et al., 2014). Some organizations were recently categorized as having a low-recovery orientation, focusing on group services (such as group homes and a common daily program), while others were identified as having a high-recovery orientation, providing effective programs for social integration (as independent housing and supported employment; Jorge-Monteiro & Ornelas, 2016).

In this sense, although the recent ordinance defines guidelines for practice, services are still provided in multiple ways that foster or fail to promote consumer-valued capabilities.

## **Research Aims and Design**

The present research contributes to the literature by adapting Nussbaum's framework (2000) for community mental health to provide both specific and contextualized dimensions and indicators of consumer-valued capabilities (aim 1), and by providing an innovative evaluative framework for community mental health and community psychology (aim 2) that will be proposed for the orientation of Portuguese community mental health programs.

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<sup>4</sup>(the DL 8/2010 is available at <https://dre.pt/application/dir/pdf1sdip/2010/01/01900/0025700263.pdf>).

The research occurred in two studies. In the first study, we adopted collaborative procedures to judge the content validity of the measure. Here, consumers are considered as experts who provide a unique and constructive form of evaluation in terms of representativeness and clarity (Rubio, Berg-Weger, Tebb, Lee & Rauch, 2003).

In the second study, we employed quantitative methods (Tabachnick & Fidell, 2013) to offer psychometric evidence regarding the factor structure and reliability of the measure in a sample of mental health consumers in Portugal.

### **Study 1 – Collaborative Analysis of Content Validity**

The goal of Study 1 was to analyze the content validity of the ACQ-CMH-104 in order to cross-check whether the items were relevant and adequate for the target population from the perspective of consumers, mental health practitioners, and academic researchers (Delgado-Rico, Carretero-Dios & Ruch, 2012). This step assures that the measure captures meaningful indicators of achieved capabilities in the context of the Portuguese mental health system.

#### **Method**

##### ***Participants***

A panel was formed of eight experts with a combined total of 124 years of experience ( $M = 15.5$ ) within the mental health system, as survivor, practitioner or researcher. The six women and two men included three consumers actively engaged in the Portuguese National Network of People with Experience of Mental Illness, three psychosocial rehabilitation practitioners randomly selected from the staff of a recovery-oriented community mental health organization (CMHO) in Lisbon, and two academic community psychologists. The mental health survivors had different diagnoses (bipolar disorder, schizophrenia, obsessive compulsive disorder) and different educational levels (high school graduate, university course work in law, engineering degree). The practitioners specialized in supportive education, supportive employment, and supportive housing; one had a master's degree in community psychology, the others had university degrees in psychology. The academic researchers both had PhD's. One specialized in measurement and the other in the capabilities approach and community mental health.

## ***Procedures***

Ethical approval of the present research was granted by the *Instituto Universitário ISPA-IU* of Lisbon, Portugal. An invitation letter was sent to all prospective panelists informing them about the overall aim of the research, the goal of the current stage of content validity, the reason they were selected, a description of the measure to be assessed, and finally, the capabilities framework and Nussbaum's list (2000) to provide the theoretical framework. All eight agreed to collaborate.

Panel members received a copy of the ACQ-CMH, composed of 104 items and ordered by 10 capabilities (Sacchetto et al., 2016), with instructions to assess each item in terms of relevance to the designated capability with a 5-point Likert scale (1 = *not relevant*; 5 = *very relevant*). For each item, participants had space to make qualitative observations, especially about clarity (phrasing and language) and adequacy (whether the item was well-related to its capability dimension). At the end of the questionnaire a space was provided asking about comprehensiveness of the questions and any suggested additions or deletions.

Researchers assembled all of the judges' qualitative comments and suggestions into a worksheet and calculated the average evaluation of relevance of each item for each subgroup, to identify any disagreement between consumers, staff and researchers, and the Content Validity Index (CVI) which is the proportion of raters who rated the item as 4 or 5 with a recommended criterion of at least .80 (Rubio et al., 2003).

These quantitative data and the qualitative worksheet were presented back to the group of experts in two two-hour meetings. The judges discussed every item to clarify wording, rectify ambiguities, and reduce overlap among items until they reached consensus on a final version of the ACQ-CMH.

## ***Results***

Looking independently at the averages of the three subgroups of the panel, the lowest scores came from practitioners who evaluated 16 items between 3.00 and 3.67 on average. Nevertheless, the proportion of agreement across raters was strong along the whole scale, with a content validity index of 0.89.

All items thus passed the quantitative criteria, but the qualitative observations suggested several adjustments to improve the measure (Delgado-Rico et al., 2012). In total, 29 items were



modified in terms of phrasing, two items were added (one consumer suggestion and one researcher suggestion), eight items were deleted because of redundancy, and two items were shifted from one capability dimension to another one. The 98 remaining items, reflecting the 10 theoretical dimensions of capabilities, were placed in a random sequence to constitute the revised version of the ACQ-CMH to be tested in Study 2.

Finally, the panel unanimously recommended a fundamental change in the response scale. They believed that a 5-point Likert scale measuring how well the program had helped the respondent to achieve a particular functioning was not appropriate because it did not include an option of *not applicable*. The ACQ-CMH reflects valued doings and beings that at least some consumers would like to realize, but considering freedom and choice, not everyone may be interested in accomplishing the same functionings. The aim is to provide opportunities to achieve what individual consumers value (Deneulin & McGregor, 2010). Therefore, the response scale was changed to a 4-point Likert scale (4 = *totally achieved*; 1 = *not achieved at all*) with an option of *not applicable* (0 = *does not apply to my situation*).

### ***Discussion***

The active involvement of lay experts “for whom the topic is most salient” - that is people with experience of mental health problems - was fundamental for the ecological validity of the measure (Rubio et al., 2003, p. 96). During the two final meetings, consumers’ opinions informed changes in items. In fact, the 29 items that were modified in terms of phrasing all involved consumers’ suggestions to ensure the appropriate content and clarity. Thus, consumer participation enhanced the cultural sensitivity of the measure.

The fact that practitioners rated some items as less relevant than did consumers may be interpreted as a sort of professional resistance. Whereas consumers make valuable contributions to research and especially to selecting outcome measures (Telford & Faulkner, 2004), professionals may mistrust consumers’ competence and not feel comfortable sharing power and decision-making (Ochocka, Janzen & Nelson, 2002). Further, the ACQ-CMH asks about functionings that consumers achieve through mental health services and support, suggesting a level of professional responsibility that may interfere in practitioners’ judgments.

## Study 2 – Psychometric analysis of the ACQ-CMH

The aim of Study 2 was to analyze the psychometric qualities including validity of the ACQ-CMH, within the community mental health context in Portugal. We conducted factor analysis and examined reliability, including re-test reliability and internal consistency, as well as discriminant and convergent validity. This step assures that the resulting instrument can be used as an evaluative framework for assessing achievement of capabilities by consumers in the Portuguese mental health system.

### Method

#### *Participants*

Table 1 describes participant characteristics (N = 333). Respondents were between 19 and 80 years of age (M = 44.14, SD = 10.93) and 59% were male. A majority were living with family (46%) or independently (30%), although only 66% said they had chosen their housing situation. The sample was about evenly divided between those who had and had not completed high school. Just over half were receiving social unemployment benefits (53%), but 62% wanted to work and 47% wanted to continue their studies. Three quarters of the sample (78%) had been hospitalized at least once and up to a maximum of 40 times (M = 3.73, SD = 4.7). The most frequent psychiatric diagnoses were schizophrenia (48%) and bipolar disorder (26%). Respondents had participated in community mental health organizations for varying periods: with a mode (29%) of 2 to 5 years.

#### *Sampling and Procedures*

A list of Portuguese non-profit community mental health organizations (CMHO), was obtained through the National Federation of Entities for the Rehabilitation from Mental Illness (*Federação Nacional de Entidades de Reabilitação de Doentes Mentais*). Twenty one that were identified as community-based organizations with declared goals and supports in line with the national guiding principles were invited to collaborate; fifteen agreed. The CMHOs are distributed throughout Portugal, but are most concentrated in the capital region. All of them are community centers and/or socio-occupational forums with similar programs regulated by the same policy concerning psychosocial rehabilitation and community services in Portugal (Decree/Law n° 8/2010 and ordinance n° 68/2017).

Eligible participants were aged 18 or older who had participated in the community mental health program for at least two months and had received a mental health diagnosis. The staff of each CMHO informed consumers about the current study, and a non-random total of 333 consumers agreed to participate. This sample corresponded to all consumers of the 15 CMHO willing to respond. A research team member visited each organization to collect data after obtaining informed consent. This person was available to assist with item comprehension, and 62% of respondents requested such assistance. Considering the population in study (51% of the study sample had up to Grade 8 in terms of education), and the general concern of literacy in a mental health context (Lincoln et al., 2017), assistance was important to ensure quality and fidelity of data collection. Completion of the full protocol (ACQ-CMH and three additional measures to assess validity) lasted around one hour, however some participants were not able to fulfil the battery of the measures.

In view of the length of the measure, a convenience sample of around 30 consumers for test-retest reliability was planned. Participants in the data collection at the first five organizations sampled were invited to repeat the ACQ-CMH 2-3 weeks later, achieving the desired sample of volunteers (n=33).

### ***Measures***

The protocol for data collection included a consent form; socio-demographic data; questions about current and past educational, professional and housing status and future aspirations; mental health experiences, including diagnosis, hospitalizations, and years of utilization of community mental health services; the 98-item version of the ACQ-CMH (Sacchetto et al., 2016, as refined in Study 1) and three additional instruments to assess validity. The ACQ-CMH-98 asks about consumers' capabilities achieved through the support of the program (items start with the statement "Through the program support I was able to..."), and included a 4-point response scale (4 = *totally achieved*; 3 = *partially achieved*; 2 = *not much achieved*; 1 = *not achieved at all*) with an option of *not applicable* (0 = *does not apply to my situation*).

The WHOQOL-Bref is a quality of life scale developed by the World Health Organization (WHOQOL Group, 1998) and already validated in Portugal (Vaz Serra et al., 2006). It is composed by 26 items, comprising two questions about overall quality of life and general health, and 24 items in four domains, namely Physical (seven items), Psychological (six

items), Social Relations (three items), and Environment (eight items). Internal consistency in the study sample was good (.78). A positive association for convergent validity with the ACQ-CMH was expected, since the capabilities approach was introduced as an alternative multidimensional framework for quality of life studies (Nussbaum & Sen, 1993).

The Recovery Assessment Scale (RAS), was originally developed by Corrigan and colleagues (2004), and further validated in the Portuguese context (Jorge-Monteiro & Ornelas, 2016). The 24-item scale has a four-factor structure including Personal Goals and Hope (11 items), Managing Help Needs (three items), Supportive Interpersonal Relationships (four items) and Beyond Symptoms (six items). Internal consistency of the RAS in this study was strong (.91). A positive association with the ACQ-CMH was expected to further support convergent validity.

The K6 measure (Kessler et al., 2003) is a nonspecific psychological distress scale composed of six items. This measure also presented good internal consistency (.83). Its brevity and accuracy in screening serious mental illness made it a good choice for discriminant validity. The Portuguese translation was performed on behalf of the WHO Composite International Diagnostic Interview Advisory Committee by Yuan-Pang Wang and colleagues.

### *Analysis*

All analyses were performed using SPSS, version 22. First, descriptive results were observed, test-retest reliability calculated (correlation and ANOVA between T1 and T2 applications), and item-total correlation examined. Second, the number of components was determined through the parallel analysis test (O'Connor, 2000), then an exploratory principal component analysis (PCA) with promax rotation was conducted (components correlated above .20), fixing the number of components to retain. Items with a factor loading < .40 and with multiple loadings (when discrepancy between the primary and secondary one was below .20) were removed one by one, with PCA repetition until a satisfactory solution was achieved (Tabachnick & Fidell, 2013). Third, the internal consistency of the obtained dimensions was assessed with Cronbach's alpha and inter-item correlations. Fourth, convergent and discriminant validity was analysed with Spearman bivariate correlations. Associations between the dimensions obtained from PCA and independent variables including housing, education, employment, and mental health profiles were observed.

## Results

### *Missing values*

Scattered missing responses (maximum 2%) were deemed Missing Completely at Random and imputed with the item average (because items varied greatly in their endorsement). Eleven participants presented  $\geq 10\%$  of missing. Because missing data is problematic for factor analyses, these respondents were excluded from the remaining psychometric analyses. The *not applicable* option in the ACQ-CMH was not considered as a missing, because it was intentionally created to reflect different choices about functionings a respondent might pursue. For psychometric analysis, we tested different approaches to scoring *not applicable*, as presented below.

### *Test-retest reliability*

Of the 98 questionnaire items, the 55% showed high to moderate reliability coefficients (.9 to  $\geq .6$ ), while 45% of the items presented low results ( $< .6$ ). ANOVA results for differences between T1 and T2 applications were also examined, and only 4 items showed significant differences ( $p < .05$ ). Three of the 98 items presented both low Pearson correlation coefficients and significant p-value for ANOVA, therefore, were considered for elimination.

### *Elimination of items prior to factor analysis*

Prior to the factor analysis, the authors removed the three items (ACQ4; ACQ8; ACQ63) with low test-retest reliability which also exceeded an absolute value of 2 of skewness and kurtosis. Finally, five items were listed as not applicable by one third or more of the respondents, so were excluded (ACQ18; ACQ33; ACQ49; ACQ50; ACQ65).

### *Exploratory principal component analysis*

A final sample of 321 participants and a 90-item version of the ACQ-CMH were used for exploratory analysis. The parallel analysis generated random data eigenvalues bigger than those found in the raw data starting with the seventh component, therefore six components were retained and subject to rotation within PCA. These analyses were conducted with three different approaches to *not applicable* responses: 1) replace these responses with the sample mean for the item; 2) analyze a correlation matrix calculated with pairwise deletion (i.e., computing each correlation using all respondents who gave answers to the two items, regardless of whether they responded to other items), 3) code *not applicable* as 1 (not achieved at all). These three methods yielded very similar factor structures. Factorial solutions for the three approaches are available

from the corresponding author by request. Although the second method can lead to internally inconsistent correlation matrices, we choose to present it here, because it uses all available data.

The obtained model explained 48.88% of the total variance and was composed of 48 items across six components. Appendix A reports details about descriptive, reliability, as well as the relationship of the items to Nussbaum's (2000) list, while Table 2 presents PCA results (factor loadings and variance explained of the final rotated component matrix).

The first component, which we labelled "Optimism," contained 13 items with a high internal consistency ( $\alpha = .91$ ) and explained the most of the variance (25.71). It evoked several dimensions of Nussbaum's list (2000). Some items recalled *emotions* (e.g. ACQ62\_be optimistic; ACQ97\_have self-esteem; ACQ6\_be hopeful about my future) and *play* (ACQ71\_have opportunities for fun; ACQ70\_enjoy my life more). Finally, this component included items about longevity and healthy lifestyle which call up the capabilities of *life* and *health* (e.g. ACQ23\_be hopeful to live a long life; ACQ94\_be hopeful to live well).

We labelled the second component, composed of nine items ( $\alpha = .84$ ), with Nussbaum's (2000) original definition of "Affiliation." Six of the items were about community integration and social relations (e.g. ACQ35\_have feelings of belonging to the community; ACQ20\_feel integrated in the community; ACQ61\_have new relationships; ACQ7\_feel respected by community members). One item was about enjoying the environment linking to Nussbaum's dimension of other species (ACQ53\_enjoy the natural environment) and another recalls Nussbaum's dimension of senses, imagination and thought (ACQ67\_be assertive). The last item (ACQ31\_feel comfortable in public spaces) pertained to bodily integrity.

The third component was labelled "Activism." Its eight items ( $\alpha = .84$ ) were about advocacy skills: (ACQ78\_advocate for the rights of people with mental illness; ACQ52\_speak in public events in mental health), peer support (ACQ51\_participate in a self-help group) and opportunities for valued social roles within the programs and the broader mental health system (e.g. ACQ42\_represent the organization or my peers in the mental health system; ACQ19\_attend public events about mental health; ACQ89\_be a member of the governance bodies of the organization). Considering Nussbaum's list of capabilities (2000) this component reflected the political aspect of *Control*, with a focus on mental health.

Nussbaum's (2000) original definition of "Practical Reason" served as a good label for the fourth component of eight items ( $\alpha = .76$ ). Contents reflected dimensions of critical awareness (e.g. ACQ91\_be aware of my physical condition; ACQ10\_have knowledge about

healthy eating), as well as responsibility and autonomy in daily life (e.g. ACQ11\_ manage domestic tasks; ACQ25\_have control over daily activities).

The fifth component was composed of seven items ( $\alpha = .76$ ) and covered the material aspect of Nussbaum's (2000) *control* and, again, *practical reason*. We labelled it "Self-sufficiency and Self-determination". Items concerned individual independence, including financial and housing dimensions (e.g. ACQ43\_become financially autonomous; ACQ69\_have access to independent housing), as well as autonomy regarding mental health issues (ACQ37\_be autonomous regarding mental health services; ACQ40\_be autonomous in the management of my medication) and power in decision-making (e.g. ACQ57\_ have decision-making power over my life).

The sixth component referred to an aspect of *affiliation* that is most specific to the life context of mental health consumers. Labelled "Family," it concerned family relationships and contained three items with good internal consistency ( $\alpha = .78$ ; ACQ45\_feel accepted by my family; ACQ88\_improve relationships with my family; ACQ16\_participate in family events).

### ***Convergent and discriminant validity***

Table 3 provides estimated bivariate correlations between the overall ACQ-CMH, its six components and the WHOQOL-Bref, RAS, and K6 measures used for validation, along with the housing independent variable. The overall score of the ACQ-CMH showed strong positive correlations with its subscales.

Convergent validity was supported by both a significant strong correlation with the quality of life measure,  $r(129) = .60, p < .001$ , and a significant moderate association with the recovery scale,  $r(92) = .46, p < .001$ . Discriminant validity was also confirmed by a low inverse correlation with the distress scale,  $r(139) = -.17(139), p = .046$ . Regarding recovery factors, the highest significant correlation was between "Optimism" and the recovery "Personal Goals and Hope" dimension,  $r(195) = .65, p < .001$ , while the weakest significant correlation was between "Family" and "Supportive Interpersonal Relationships",  $r(184) = .19, p = .009$ .

The "Self-sufficiency and Self-Determination" dimension was also highly associated with housing, correlating positively,  $r(329) = .34, p = .001$ , with living independently and negatively,  $r(329) = -.32, p = .001$ , with living with family.

## Discussion

The ACQ-CMH-48 presents a solution of six dimensions with good psychometric properties, and suggests a reorganization of Nussbaum's ten capabilities (2000) for the study context. The obtained components are well-aligned with community psychology theory and values and offer an inspiring evaluative framework for community mental health. The first component of the ACQ-CMH, "Optimism", includes items concerning hopefulness and self-confidence that evoke the recovery factor of "Personal Goals and Hope" (Corrigan, Salzer, Ralph, Sangster & Keck, 2004). The significant positive correlation within these two sub dimensions corroborates the coherence of the models. The contents of this component also recall concepts of self-efficacy, motivation and control reflecting the intrapersonal level of the psychological empowerment (Zimmermann, 2000). The last indicators introduce content about health and quality of life which are contextually pertinent due to the target population's health issues (Newcomer, 2007). Beyond feelings of hope and orientation toward the future, health and longevity issues are crucial for personal recovery and empowerment processes.

The "Affiliation" component encompasses elements of community integration (Wong & Solomon, 2002), such as interpersonal connectedness, social networks and community. It evokes community psychology principles of social inclusion and social justice which underline equal and non-discriminant access to community resources (Nelson et al. 2017). Other elements as having a respectful and comfortable relation with the natural environment and public spaces may be seen as inspiring community integration in theory and practice, considering that the population of people with mental health challenges still suffer public stigma and structural discrimination (Hamilton et al., 2016).

"Activism" corresponds to Nussbaum's (2000) dimension of political control, with explicit reference to the opportunity structure of valued roles within the organization and the broader mental health system (Maton, 2008). Literature about recovery-oriented mental health policies supports consumers' involvement and leadership to identify their needs and concerns as well as to obtain unique insights into social justice (Piat & Polvere, 2014). Consumers retain the perspective of those who directly experience mental health challenges and social exclusion. In this sense, programs should provide possibilities for active participation in policy events, among other broader opportunities for consumers to be leaders in the process of transformative change.

The component of activism also includes peer support and mutual aid. Community



psychologists have contrasted this consumer-led support with mainstream professional treatment (Nelson et al., 2017).

“Practical Reason” reflects consumers’ awareness and responsibility in daily life. Nussbaum affirms that *practical reason* and *affiliation* suffuse all the others (Nussbaum, 2000). In the current study the *practical reason* seems to have a central role. “Self-Sufficiency and Self-determination” is also quite related to it, although it focuses on different aspects as the self-management of money, of mental health issues, and the independence regarding housing and family. Some indicators of problem-solving processes in this dimension recall the interactive component of the psychological empowerment (Zimmerman, 2000).

The “Family” dimension reflects consumers’ concerns to improve their relationship, and feelings of acceptance and belonging. This finding is pertinent considering that consumers still suffer lack of support and discrimination within the family (Hamilton et al., 2016). The weak association between “Family” and “Supportive Interpersonal Relationships” reinforces the idea that support within the family context is often scarce. This last component needs to be interpreted in the context of the “Self-sufficiency and Self-determination” scale, where independence from the family is explicit. Correlational results also suggest greater self-sufficiency when consumers are integrated in independent housing rather than living with relatives. In terms of intervention, this may suggest that the programs should promote relationships of mutual respect and acceptance with family, at the same time as promoting self-sufficiency and autonomy, for example, with independent housing and supported employment.

### **Implications for Practice and Research**

The research provides important guidance for transformative change of mental health programs in Portugal. Consumers, especially in Study 1, confirmed their willingness to collaborate and to influence mental health research, which is in line with other literature (Telford & Faulkner, 2004). The principal component analysis of Study 2 also emphasized the dimension of consumers’ activism and political control, with content about specific opportunities for influence within both organizations and the mental health system. The importance of an opportunity role structure was identified as a crucial organizational feature of empowering settings in recent national studies; individuals need to access and participate at diverse capacity-building opportunities (Jorge-Monteiro et al., 2014). Therefore, promoting consumer involvement in valued formal roles for policy and governance, such as membership

on an organization's board of directors, is strongly recommended.

Considering that the target population has historically suffered from lack of self-determination, promoting consumers' ability to be aware and autonomous in various life domains - such as daily routines, housing, family, financial and mental health issues - is essential. Community mental health programs should pursue consumers' critical awareness and reflection; collaborative processes such as sharing power and knowledge may be a tool to accomplish these goals (Ochocka et al., 2002). The community psychology principle of collaboration between professionals and consumers entails shared responsibilities and resources and is a core strategy to promote a system change (Piat & Polvere, 2014).

In order to support consumers' independence and self-sufficiency regarding housing and financial issues, independent housing and supported employment are possible social responses. These flexible and diversified services rely on consumers' choice in ways consistent with the capabilities framework (Hopper, 2007; Nelson et al., 2017). Future studies should explore the effect of these services in the achievement of capabilities.

The ACQ-CMH could also be used in further studies to evaluate the extent to which a program enhances capabilities for its participants. Both the *average* level of achievement of capabilities by participants in a program and the *range* of different achievements that a program supports are relevant. That is, the extent to which different participants choose and achieve different goals is a measure of the extent to which the program enhances participants' freedom to do and be (Shinn, 2015). Calculating the mean number of items participants in a particular program have achieved is straightforward. In order to compare the variation in achievements by participants in programs of different sizes, a metric that is independent of program size is needed. We suggest a modification of a standard entropy measure from information theory.<sup>5</sup>

Finally, future work may also address how to incorporate *not applicable* responses in the measure. This option was purposefully added to reflect consumer's choice about which beings and doings to pursue. One option could be to obtain the individual overall score of achieved capabilities as a proportion of items an individual judged to be relevant (excluding the *not applicable* items).

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<sup>5</sup> The sum, across items of  $-\ln p(1-p)$  where  $p$  is the mean attainment of a particular item divided by the mean total attainment across items for that program. For example, on a short 4-item measures, a program where all participants attained the same one item, the entropy measure would be zero. A program where half of participants attained each of two items, and a program where a quarter of participants attained each of the four items would both have the same mean attainment of 1, but entropy scores of 0.69 and 1.39, respectively.

### **Limitations and Further Directions**

The research has some limitations. First of all, the difficulty of reaching a large, representative sample of this population led to a convenience sample and a relatively low number of respondents per item for EFA. However, according to Guadagnoli & Velicer (1988), 300 is an acceptable minimum of sample size when few variables defined factors with moderate to low loadings. Moreover, future studies will aim to confirm the factorial model (using confirmatory factor analysis) through new data collection. At the same time, further analysis will help refine the measure, making it shorter and more precise. This will address another study limitation, that is, the length of the scale.

The context-specific nature of the instrument may limit the measure's generalizability to other systems or groups. However, a cross-cultural validation study is of major interest. The authors advocate an initial research phase to assess content validity through collaborative processes. That way, the adequacy and relevance of the items may be adjusted for context and culture. International partnership have already been established for follow-up studies (i.e. with one Italian and one North American university), with the aim of initiating cross-cultural translation and adaptation, as well as validation of the ACQ-CMH.

Finally, collaborative procedures, which are particularly consistent in the community mental health field, are strongly recommended in the development of capabilities measure. Future studies should keep looking for an active involvement of consumers, by providing them spaces of decision-making and leadership within specific research tasks.

### **Conclusion**

The Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH) is an instrument to evaluate the extent to which mental health programs foster consumer's gains in achieving capabilities. It offers contextualized and meaningful indicators and dimensions, as well as psychometric and validity evidence.

The process for developing the ACQ-CMH ensured that the items and scales are close to consumers' experiences and expectations, thus enhancing the ecological and cultural sensitivity of the measure based on consumer-valued beings and doings (Rubio et al., 2003). The validated measure of achieved capabilities may contribute to evaluation of community mental health programs in Portugal.

This adaptation of Nussbaum's capabilities list (2000) enhances the shift from deficit-oriented models of intervention to ecological services, encompassing community psychology values of empowerment, inclusion, social justice, self-determination, and valued social roles (Nelson et al., 2017). It provides a new evaluative framework that may inspire community psychology efforts to promote a transformative change in community mental health.

By specifying achieved capabilities that are important to consumers, and measuring how well programs succeed or fall short of helping consumers to attain them, we hope that the ACQ-CMH can both motivate and guide change efforts.

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Table 1

*Participant Characteristics*

Variables	<i>n</i>	Mean(SD), %	Variables	<i>n</i>	Mean(SD), %	Variables	<i>n</i>	Mean(SD), %
Age (years)	332	44.14(10.93)	Education			Diagnosis		
			Without school	10	3	Schizophrenia	135	48
Gender			Grade 4 or less	39	12	Bipolar Disorder	73	26
Female	135	40	Grade 5 to 8	119	36	Major Depression	33	12
Male	197	59	High School	104	31	Other	44	16
			Higher Education	49	15			
Marital Status			Wish to study			Hospitalization		
Single	253	76	Yes	154	47	Yes	260	79
Married/co-habiting/partnered	34	7	No	178	53	No	71	21
Separated/divorced	47	14						
Widowed	8	2	Employment			Number of Hospitalizations	249	3.73(4.70)
			Employed	37	11			
Housing			Volunteer/Intern	11	4	Time in CMHO		
Family	151	46	Unemployed	57	17	≥ 6 months	28	9
Independent	100	30	Retired	42	13	7 months - 1 year	37	12
Group Home	68	20	Social Benefit	177	53	2 - 5 years	94	29
Other	12	4	Other	8	2	6 - 10 years	74	23
			Wish to work			11 - 15 years	51	16
Housing Choice			Yes	201	62	16 - 20 years	21	7
Yes	222	66	No	124	38	≤ 21 years	8	3
No	110	33						

*Note.* % values may not add to a total of 100% due to rounding.

Table 2  
*Rotated Component Matrix Loading*

	Component					
	Optimism	Affiliation	Activism	Practical Reason	Self-Suff Self-Deter	Family
ACQ70	.930			-.206		
ACQ62	.754					
ACQ39	.738					
ACQ97	.656					
ACQ94	.618					
ACQ84	.605			.334		
ACQ64	.544			.255		
ACQ6	.534	.215				
ACQ71	.534					
ACQ92	.525					
ACQ32	.510	.264				
ACQ23	.508	.219				
ACQ86	.458				.240	
ACQ20		.642				
ACQ35		.637		-.256		
ACQ66		.613				
ACQ61		.591				
ACQ2		.576				
ACQ53		.563				
ACQ7		.559				
ACQ31		.521				
ACQ67		.458			.256	
ACQ42			.700			
ACQ19	-.211		.686			
ACQ52			.677			
ACQ51			.647			
ACQ78			.616			
ACQ29			.616			
ACQ24			.583			
ACQ89			.576		.240	
ACQ11				.639		
ACQ91				.637		
ACQ90				.580		
ACQ79		.201		.579		
ACQ48				.566		
ACQ82				.564	.206	
ACQ25				.549		
ACQ10				.543		
ACQ43					.768	
ACQ69		-.292			.635	
ACQ37	-.313	.355			.623	
ACQ34					.615	.250
ACQ40					.607	
ACQ55		-.239			.590	
ACQ57					.573	
ACQ45						.845
ACQ88						.828
ACQ16						.658
% of variance	25.71	6.98	4.83	4.34	3.23	3.20
<b>Tot. variance</b>	<b>48.88</b>					

Table 3

*Pearson Correlations of the ACQ-CMH with its components, WHOQOL-Bref, RAS, K6 measures and independent variables*

Scale	ACQ-CMH	ACQ						WHO		Housing	
		ACQ1	ACQ2	ACQ3	ACQ4	ACQ5	ACQ6	QOL	RAS	Independent	Family
ACQ-CMH										-.05 <sup>b</sup>	-.12
ACQ1. Optimism	.86									.03 <sup>b</sup>	-.06 <sup>b</sup>
ACQ2. Affiliation	.83	.73								.05 <sup>b</sup>	-.03 <sup>b</sup>
ACQ3. Activism	.73	.32	.45							-.16 <sup>a</sup>	.00 <sup>b</sup>
ACQ4. Practical Reason	.76	.57	.52	.30						.07 <sup>b</sup>	-.17
ACQ5. Self-Suff/Deter	.69	.47	.40	.40	.42					<b>.34</b>	<b>-.32</b>
ACQ6. Family	.51	.33	.33	.25	.29	.20				-.15 <sup>a</sup>	.15
WHOQOL-Bref	<b>.60</b>	.67	.57	.26	.44	.25	.22				
K6	<b>-.17<sup>a</sup></b>	-.35	-.19	-.03 <sup>b</sup>	-.07 <sup>b</sup>	-.19	-.01 <sup>b</sup>	-.33	-.36		
RAS	<b>.46</b>	.65	.47	.11 <sup>b</sup>	.31	.26	.19 <sup>a</sup>	.59			
RAS.PGH	.47	<b>.65</b>	.43	.12 <sup>b</sup>	.30	.26	.15 <sup>a</sup>				
RAS.MHN	.14 <sup>b</sup>	.27	.26	-.00 <sup>b</sup>	.14 <sup>b</sup>	.14 <sup>b</sup>	.07 <sup>b</sup>				
RAS.SIR	.31	.32	.34	.15 <sup>b</sup>	.21	.08 <sup>b</sup>	<b>.19</b>				
RAS.BS	.37	.56	.35	.06 <sup>b</sup>	.27	.27	.18 <sup>a</sup>				

*Note.* ACQ-CMH = Achieved Capabilities Questionnaire for Community Mental Health; WHOQOL-Bref = World Health Organization Quality of Life Bref; K6 = Psychological Distress Scale; RAS-P = Portuguese version of the Recovery Assessment Scale (PGH = Personal Goals and Hope; MHN = Managing Help Needs; SIR = Supportive Interpersonal Relationships; BS = Beyond Symptoms). Correlations are significant at  $p < .01$  level, with the exceptions given in the footnotes.

<sup>a</sup> Significant at  $p < .05$  level    <sup>b</sup> Not significant at  $p < .05$ .

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**Appendix A.** Descriptives, reliability, and relationship to Nussbaum's list of the ACQ-CMH-48 items

Scale/Item	Nussbaum's capabilities (2000)	Mean (SD)	Ske	Kur	Item-Total Correlation	$\alpha$
<b>ACQ1. Optimism</b>		<b>3.18(.59)</b>				<b>.91</b>
ACQ70_enjoy my life more	Play	3.22(.89)	-1.05	.40	.72	
ACQ62_be optimistic	Emotions	3.17(.93)	-.99	.11	.68	
ACQ39_be joyful	Emotions	3.11(.89)	-.72	-.30	.65	
ACQ97_have self-esteem	Emotions	3.17(.91)	-.10	.23	.70	
ACQ94_be hopeful to live well	Life & Health	3.16(.92)	-.94	.03	.61	
ACQ84_have self-confidence	Emotions	3.26(.80)	-.93	.40	.58	
ACQ64_think about useful things for my life	Practical Reason	3.35(.82)	-1.13	.62	.54	
ACQ6_be hopeful about my future	Emotions	3.16 (.90)	-.96	.12	.61	
ACQ71_have opportunities for fun	Play	3.19(.92)	-.92	-.06	.58	
ACQ92_be relaxed	Life & Health	3.07(.88)	-.69	-.25	.55	
ACQ32_value my capacities	Emotions	3.19(.84)	-.90	.29	.62	
ACQ23_be hopeful to live a long life	Life & Health	3.15(.90)	-.85	-.09	.61	
ACQ86_feel emotionally stable	Emotions	3.15(.85)	-.82	.09	.65	
<b>ACQ2. Affiliation</b>		<b>3.22(.56)</b>				<b>.84</b>
ACQ20_feel integrated in the community	Affiliation	3.22(.86)	-.98	.32	.67	
ACQ35_have feelings of belonging to the community	Affiliation	3.17(.86)	-.97	.44	.61	
ACQ66_interact with community members	Affiliation	3.17(.87)	-.80	-.14	.62	
ACQ61_have new relationships	Affiliation	3.08(.95)	-.75	-.43	.59	
ACQ2_be sociable	Affiliation	3.29(.80)	-1.06	.74	.44	
ACQ53_enjoy the natural environment	Other species	3.32(.87)	-1.26	.88	.47	
ACQ7_feel respected by community members	Affiliation	3.30(.83)	-1.10	.63	.50	
ACQ31_feel comfortable in public spaces	Bodily Integrity	3.28(.86)	-1.08	.44	.57	
ACQ67_be assertive	Senses, Imagination & Thought	3.17(.86)	-.84	.01	.54	
<b>ACQ3. Activism</b>		<b>2.46(.72)</b>				<b>.84</b>
ACQ42_represent the organization or my peers in the mental health system	Control (A. Political)	2.57(1.20)	-.13	-1.52	.70	
ACQ19_attend public events about mental health (e.g. conferences)	Control (A. Political)	2.75(1.19)	-.43	-1.33	.57	
ACQ52_speak in public events about mental health (e.g. conferences)	Control (A. Political)	2.06(1.18)	.53	-1.31	.71	
ACQ51_participate in a self-help group (with people with mental illness experience)	Control (A. Political)	2.63(1.27)	-.21	-1.62	.52	
ACQ78_advocate for the rights of people with mental illness	Control (A. Political)	2.86(1.12)	-.54	-1.10	.62	
ACQ29_have formal membership in the organization	Control (A. Political)	2.75(1.35)	-.37	-1.70	.51	
ACQ24_have opportunities to volunteer	Control (A. Political)	2.37(1.22)	.15	-1.57	.50	
ACQ89_be a member of the governance bodies of the organization	Control (A. Political)	1.71(1.11)	1.14	-.36	.52	
<b>ACQ4. Practical Reason</b>		<b>3.33(.49)</b>				<b>.76</b>
ACQ11_manage domestic tasks	Practical Reason	3.24(.86)	-1.03	.42	.56	
ACQ91_be aware of my physical condition	Practical Reason	3.41(.79)	-1.24	.93	.50	
ACQ90_attend appointments regularly	Practical Reason	3.46(.76)	-1.35	1.26	.45	
ACQ79_have sense of responsibility	Practical Reason	3.47(.70)	-1.40	2.04	.57	

ACQ48_take care of my physical condition	Practical Reason	3.37(.84)	-1.31	1.02	.44
ACQ82_prepare my own meals	Practical Reason	2.96(1.10)	-.64	-.98	.42
ACQ25_have control over daily activities	Practical Reason	3.33(.71)	-.89	.70	.45
ACQ10_have knowledge about healthy eating	Practical Reason	3.39(.77)	-1.15	.77	.37
<b>ACQ5. Self-sufficiency and Self-determination</b>		<b>2.87(.65)</b>			<b>.76</b>
ACQ43_become financially autonomous	Control (B. Material)	2.66(1.12)	-.31	-1.28	.60
ACQ69_have access to independent housing	Control (B. Material)	2.09(1.32)	.55	-1.52	.40
ACQ37_be autonomous regarding mental health services	Practical Reason	3.08(.95)	-.78	-.36	.46
ACQ34_manage my money	Control (B. Material)	3.14(.97)	-.89	-.28	.47
ACQ40_be autonomous in the management of my medication	Practical Reason	3.37(.97)	-1.4	.14	.43
ACQ55_become independent from my family	Control (B. Material)	2.68(1.10)	-.28	-1.25	.53
ACQ57_have decision-making power over my life	Practical Reason	3.08(.96)	-.85	-.22	.53
<b>ACQ6. Family</b>		<b>2.86(.41)</b>			<b>.78</b>
ACQ45_feel accepted by my family	Affiliation	3.12(1.01)	-.94	-.23	.68
ACQ88_improve relationships with my family	Affiliation	3.04(.98)	-.87	-.23	.64
ACQ16_participate in family events	Affiliation	2.84(1.08)	-.56	-.95	.53
<b>ACQ-CMH-48 items</b>		<b>2.86(.41)</b>			<b>.94</b>

*Note.* ACQ-CMH-48 items = Achieved Capabilities Questionnaire for Community Mental health - 48 items version.

Scales and items were ordered basing on decreasing values of variance explained and factor loadings.

\*\* Significant at  $p < .01$  level \* Significant at  $p < .05$ .



**Article III – Confirmatory Study of the Achieved Capabilities Questionnaire for  
Community Mental Health (ACQ-CMH): A Consumer-based Outcome Measurement**





## **Confirmatory Study of the Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH): A Consumer-based Outcome Measurement**

### **Abstract**

A growing number of measures grounded in the capabilities approach for outcome measurement are appearing, revealing an innovative evaluative framework. In particular, consumer-valued measures—constructed in collaboration with people who have the experience of mental illness and service participation—are here considered crucial for a transformative contribution to the mental health system. Meanwhile, researchers have to provide evidence of new measurement properties to enable a proper choice and application in research and intervention.

The Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH) was developed in collaboration with consumers of community mental health services in Portugal to obtain a consumer-based outcome measurement. It aims to assess consumers' capabilities achieved through the support of community mental health programs and services. The ACQ-CMH was already examined in terms of psychometric qualities, including an exploratory factor analysis that provided a 48-item and 6-factor structure. The present paper reports advancements in the measure validation. Specifically, the structure obtained by the previous exploratory study was tested within a sample of community mental health consumers ( $n = 225$ ). Reliability, factor sensibility, and construct-related validity (convergent and discriminant) were also observed.

A new structural solution composed of five factors and 43 items reveals a better model fit than the one obtained in the exploratory study. In other words, two dimensions—called self-determination and control—were joined into one, showing psychometric and theoretical consistency. Findings support the reliability, sensibility, and both convergent and discriminant validity of using the ACQ-CMH in the evaluation of community mental health interventions.

*Keywords:* capabilities approach, consumer-based outcome measurement, community mental health, psychometric validation, confirmatory factor analysis

## Introduction

The capabilities approach has gained visibility among diverse scientific fields in the last decades. It has emerged as an alternative framework for evaluating the quality of life, taking into account broader dimensions of well-being than standard utilitarian approaches (Sen, 1992). Capabilities, which are *beings* and *doings* people value and choose (Nussbaum & Sen, 1993), are intended within a societal perspective and therefore defined as *combined capabilities* as well, comprising both internal or personal characteristics and external possibilities (Nussbaum, 2011) that depend on social, political, familiar, and economic conditions. Nussbaum (2000) advanced a list of 10 capabilities for a worthy quality of life that encompass broad dimensions, such as *emotions*, *affiliation*, *practical reason*, and *control over one's environment*, which are recommended to be adapted to the specificity of each context and culture (Nussbaum, 2011). Nussbaum's account has been discussed as a useful framework for evaluating one's environment, providing for critical reflection on contextual and institutional barriers or facilities, especially for populations in disadvantaged conditions (Shinn, 2015). People who experience mental health challenges are a social group that has historically suffered discrimination and limitation of freedom (Nelson et al., 2017) and who still experience unfair economic, health, and social outcomes (Brunner, 2017). Therefore, the call for a critical analysis of the institutional structures of support is urgent. The capabilities approach offers guidelines for rethinking the consumers' role, restoring their agency and control over their lives (Wallcraft & Hopper, 2015), as well as their right to choose within socially valued opportunities for integration and citizenship (Hopper, 2007). For mental health research, the capabilities framework may serve for evaluating the extent to which services or programs foster consumers' capabilities (Sacchetto et al., 2018).

The capabilities concept refers to freedoms or possibilities to do and to be (Nussbaum & Sen, 1993) that, when achieved, are called functionings or functional capabilities. The conceptual distinction between capability and functioning is underlined in the capabilities literature to strengthen the individual act of choice and to contrast oppressive systems with social responses that support people in achieve their potential (Shinn, 2015). But how can individual possibility be measured? And how can the efficacy of care interventions in promoting freedoms to be and to do be captured? We believe that a capabilities measure for possibilities and potential opportunities may not respond to the urgent question: Are services helping people to achieve what they value? Especially in the case of people with mental health problems who have historically suffered dependency on the mental health system, it is

necessary to study the impacts of intervention models on individual outcomes (Ornelas, et al., 2019). For this purpose, new measures that take into account consumers' perspectives are needed in order to foster their right to participate in service planning and evaluation (Wallcraft & Hopper, 2015). This is even more important because the majority of outcome measures in mental health were developed by professionals and researchers without consumers' involvement (Rose et al., 2011). The lack of participative approaches led to a definition of service outcome that may not be relevant for them or reflect their values and experiences, which is not recommended when researching quality of life (Thornicroft & Tansella, 2010). In this sense, this paper offers a measure, developed in previous studies in collaboration with people with mental illness experience, which tends to assess and monitor if programs are really promoting the achievement of consumer-valued capabilities.

For the evaluation of effective mental health interventions, research instruments that shift from an illness-centered to a capabilities-oriented measure are recommended, encompassing recovery and empowerment promotion (Nelson et al., 2014; Ornelas et al., 2019). Empowerment, which focuses on mastery and personal power, and recovery, which refers to self-determination and meaningful connectedness within community life, were largely discussed to orient mental health services and interventions (Corrigan, 2006; Farkas et al., 2005). These concepts are theoretically coherent and interconnected with the capabilities perspective, which has been proposed to further contribute to a systemic transformation and evaluation (Davidson et al., 2009; Hopper, 2007; Nelson et al., 2014).

### **Capabilities Measures for Outcome Evaluation**

Regarding evaluation and measurement, the capabilities framework has inspired interdisciplinary studies, comprising social and health sciences (Helter et al., 2019). A growing number of capabilities measures has appeared, in particular outcome measures (Lorgelly et al., 2015). Regarding health, the capabilities approach proposes an alternative framework for assessment of interventions considering health and non-health effects (Mitchell et al., 2015; Mitchell et al., 2017). For mental health measurement, this is particularly pertinent because it endorses the value of non-health outcomes such as recovery, empowerment, and social integration (Ornelas et al., 2019; Shinn, 2015).

Helter et al. (2019) presented a literature review on capabilities instruments for the evaluation of health-related interventions. Fourteen newly developed instruments were

identified, most of them with some evidence of psychometric properties, although further information about practical and theoretical characteristics of these measures is recommended in order to properly choose and apply them in both research and intervention. Another recent systematic review about capabilities measurement in health, identified eleven questionnaires with good validity and reliability evidence (Till et al., Under Revision). These two literature review identified, so far, two capabilities instruments for mental health in intervention assessment (Helter et al., 2019; Till et al., Under Revision). Both are multi-dimensional and self-reported measures. The first was developed based on a refinement of a capability instrument (OCAP-18) for the assessment of public health interventions in Glasgow (Lorgelly et al., 2010; Lorgelly et al., 2015). The process of refinement for mental health research (Simon et al., 2013) has been based on expert focus groups composed only of professionals, such as psychiatrists and psychologists, and on content validity and feasibility within a group of users of Community Treatment Orders in the UK. The resulting mental health version is called the Oxford Capabilities Measure for Mental Health (OxCAP-MH), and it has been further tested to find out its psychometric properties, such as reliability, validity, responsiveness, and feasibility (Łaszewska et al., 2019; Simon et al., 2013; Vergunst et al., 2017). More recently, it was also translated and adapted to the German context (Łaszewska et al., 2019; Simon et al., 2018). However, participatory processes within the developmental process were scarce.

The second capabilities instrument for mental health is the Achieved Capabilities Questionnaire for Community Mental Health (ACQ-CMH) presented in this paper. It was developed by following a collaborative approach with consumers of community mental health services (Sacchetto et al., 2016) in order to obtain a consumer-driven research instrument for intervention assessment. For the measure's development, Nussbaum's framework inspired both the data collection and analysis, always through collaborative procedures. For the data collection, focus groups with 50 consumers were organized, while data were analyzed by a steering committee composed of three consumers and two researchers to identify a pool of items and sort them according to Nussbaum's list. This participatory effort led to a questionnaire with 104 indicators organized by Nussbaum's account of 10 capabilities (Nussbaum, 2000, 2011) that reflect consumers' definitions of *beings* and *doings* they value, i.e., their aspirations within their service paths. Considering that a key element of the capabilities approach is the act of choice, choosing indicators of capabilities seems not only logical but required. The first version of the measure, composed of 104 items and ordered by the 10 capabilities, was then refined in a subsequent study based on psychometric analysis (Sacchetto et al., 2018). First, content

validity was assessed involving again consumers beyond staff members and researchers, leading to the creation of a revised version of 98 items. Then, the 98-version was tested in terms of reliability and validity, including exploratory factor analysis (EFA), with a sample of community mental health consumers ( $n = 332$ ). The factorial analysis (through PCA) and the parallel analysis test indicated a structure composed of 48 items and six dimensions with good psychometric properties (Sacchetto et al., 2018). In this sense, Nussbaum's account was revisited and adapted within the study context, obtaining specific dimensions and indicators of capabilities for people with mental illness experience. More details about the theoretical framework of the ACQ-CMH, its relevance in community mental health, the process of development, as well as the EFA study, are available elsewhere (Sacchetto et al., 2016; Sacchetto et al., 2018).

This paper aims to report advancements on the validation study of the 48-item and six-factor version of the ACQ-CMH in order to find a robust research instrument for the evaluation of outcome measurements within community mental health interventions. Therefore, psychometric properties with a sample of community mental health consumers ( $n = 225$ ) were examined, namely (a) factorial validity, through confirmatory factor analysis (CFA) (Kline, 2015), to check the factorial structure obtained by the previous EFA study (Sacchetto et al., 2018); (b) reliability; (c) sensibility regarding professional and housing status; and (d) construct-related validity, including convergent and discriminant validity, where the relationships between the ACQ-CMH and quality of life, recovery, empowerment, and distress measures were observed. Considering that the capabilities approach was originally proposed as an innovative framework to study the quality of life (Nussbaum & Sen, 1993), this construct was considered essential for proving a significant relationship for convergent validity. Positive associations between recovery and empowerment scales with the ACQ-CMH were hypothesized to further support convergent validity. Finally, distress was expected to be negatively associated with the achievement of capabilities for divergent validity.

## **Method**

### **Participants and Sampling**

Participants in this study ( $n=225$ ) were consumers of community mental health programs aged between 18 and 76 years ( $M = 41.03$ ,  $SD = 12.43$ ), and 44% were female. Almost all participants were Portuguese (95%) and Caucasian (90%), while 7% were from an African

ethnic group, and nine participants (4%) had a nationality within the Portuguese-speaking African countries. The majority were single (78%) and without children (79%). Three-quarters of the sample (74%) knew their psychiatric diagnoses, and nearly half reported a schizophrenia diagnosis (45%), while one-quarter reported a bipolar disorder (24%). Of the participants, 63% had experienced psychiatric hospitalizations, and among this group, almost a third (30%) were hospitalized once. The number of hospitalizations varied between one and 23 times ( $M = 3.54$ ,  $SD = 3.65$ ). Half of the participants (52%) lived with family, while 18% lived in group homes and 30% independently. The sample was divided between those who were not (55%) and those who were (45%) willing to move to another housing solution, mostly towards independent housing (71%). About half of the sample had high school education (53%) and wished to continue studying (43%). Seventy-nine percent joined educational/training courses through the educational services of the programs they were attending. Regarding professional status, 78% were professionally inactive, either unemployed, retired, or receiving a social benefit—mostly a disability pension (36%). Fifty participants (22%) were professionally committed, but only 18 of them (8%) were regular paid workers, while the remaining were trainees or volunteers. Of the working group, 78% were supported by the program's employment services. On average, respondents had not been working for two decades ( $M = 19.20$ ,  $SD = 13.75$ ), although about half of the sample (55%) declared they were willing to start a new job. Utilization of service time varied from two months to 30 years ( $M = 6.31$  years,  $SD = 6.44$  years).

The convenience sample was retrieved from the Portuguese community-based mental health response, based on community programs. Most are non-profit organizations, guided by psychosocial rehabilitation policies (Decree/Law n°8/2010; legal ordinance n° 68/2017)<sup>6</sup> that emphasize the need for consumer independency, self-determination, and full citizenship. In line with these policies, common goals of these community structures are recovery, empowerment, social integration, and participation.

Each of the 15 community-based organizations that had participated in the previous exploratory study (Sacchetto et al., 2018) were contacted again to ask for new participants who had not responded in the previous phase. Meanwhile, findings obtained by the previous EFA study were shared. Nine of these organizations accepted collaboration again, having integrated new consumers since the last data collection. In order to achieve an acceptable sample for the confirmatory analysis, eight more community programs were contacted and invited. Only two

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<sup>6</sup> The DL n° 8/2010 is available at <https://dre.pt/application/conteudo/616776>, and the legal ordinance n° 68/2017 is available at <https://dre.pt/application/conteudo/106471884>

of them accepted participation. In total, 11 community programs participated in this study, nine situated in the capital region, one in the north and one in the south of the country. In all, 23 services and programs were contacted, corresponding to all the community mental health organizations listed by the National Federation of Entities for the Rehabilitation from Mental Illness (*Federação Nacional de Entidades de Reabilitação de Doentes Mentais*<sup>7</sup>).

## Measures

The protocol for data collection was almost the same as the one used in the previous exploratory study. At all, five research instruments were included:

The *Achieved Capabilities Questionnaire for Community Mental Health* (ACQ-CMH-48) (Sacchetto et al., 2018), composed of 48 items across six dimensions and identified as the hypothesized or theoretical model to be tested here. The six dimensions of the ACQ-CMH-48 are: Optimism (13 items), Affiliation (nine items), Activism (eight items), Practical Reason (eight items), Self-Sufficiency and Determination (seven items), and Family (three items). The ACQ-CMH aims at measuring consumers' capabilities achieved through the support of community mental health interventions. Items promote an individual's critical reflection about consumers' paths within the programs, starting with the statement "Through the program support I was able to. . ." and comprising a four-point response scale, ranging from *totally achieved* (4) to *not achieved at all* (1);

The *WHOQOL-Bref* (WHOQOL Group, 1998), which is the 26-item version of the quality of life scale developed by the World Health Organization. The first two items are general questions about health and quality of life satisfaction, and the other 24 items are distributed across four domains: Physical (seven items), Psychological (six items), Social Relations (three items), and Environment (eight items). This measure was already validated in Portugal (Vaz Serra et al., 2006). Internal consistency in the present study sample was quite good (.84);

The *K-6 Distress Scale* (Kessler et al., 2003), a short scale composed of six items to measure nonspecific psychological distress, where a higher score indicates greater distress and symptom severity. The WHO Composite International Diagnostic Interview Advisory Committee by Yuan-Pang Wang and colleagues performed the Portuguese translation. This measure also presented good internal consistency in the present study (.84);

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<sup>7</sup> <http://www.fnerdm.pt/>

The *Recovery Assessment Scale* (RAS-P), originally developed by Corrigan et al. (2004) and already validated for the Portuguese context (Jorge-Monteiro & Ornelas, 2016). The 24-item structure presents four domains— Personal Goals and Hope (11 items), Managing Help Needs (three items), Supportive Interpersonal Relationships (four items), and Beyond Symptoms (six items). Internal consistency of the RAS in this study was almost excellent (.89);

Finally, the Portuguese version of the *Empowerment Scale*, (ES-P) (Jorge-Monteiro & Ornelas, 2014), which is a consumer-constructed measure (Rogers et al., 1997). It consists of 25 items and a four-factor structure, including Self-esteem and Efficacy (nine items), Powerlessness Relations (seven items), Optimism and Control over the Future (three items), Righteous Anger (three items), and Community Activism and Autonomy (six items). This measure presented a suitable internal consistency in the study (.78).

The protocol also included socio-demographic variables and questions about educational, professional and housing achievements and goals, and mental health experiences such as diagnoses, hospitalizations, and participation in community mental health services.

## **Procedures**

Data were collected in paper form at the community structures after consent form assignment. Aims, procedures, and anonymity issues were reinforced orally as well. A research member supported the data collection when there were comprehension or literacy issues (40.9% asked for assistance) and appealed to participants to respond to each question, especially in order for the ACQ-CMH measure to be validated. The response to the full protocol lasted about one hour, but not everyone was able to fulfill all the measures. Criteria for participants' eligibility were age (minimum 18 years); time within the community mental health programs (minimum two months); and a current mental illness experience.

The research was approved by the ethics committee of the XXX in Lisbon, Portugal.

## **Data Analysis**

Psychometric and validity properties of the six-factor and 48-item version of ACQ-CMH-48, identified in this study as the hypothesized model, were examined. Before the confirmatory technique, pre-analysis and screening procedures were performed to check normality, outliers, linearity, and multicollinearity. Problematic items distribution with respect to absolute values greater than two for both skewness and kurtosis were observed (Kilne, 2005). Next, CFA with maximum likelihood estimation was employed to evaluate the model fit. Several commonly reported goodness-of-fit indices were compared to analyze the model



adequacy: The chi-square statistics ( $\chi^2$ ) statistics, the Comparative Fit Index (CFI), the Tucker Lewis Index (TLI), and the Root Mean Square Error of Approximation (RMSEA), as well as the Expected Cross-Validation Index (ECVI) and the Modified ECVI (MECVI) for comparative purposes. The  $\chi^2/df$  is recommended to be between 1.0–2.0 for adequate models (Hair et al., 2014). For CFI and TLI, indexes below .85 show a poor model fit, the range between .85 - .90 indicates a mediocre but tolerable fit, while .90 or above is considered a good fit (West et al., 2012). A reasonable fit is indicated also by an RMSEA between .05 and .08 (Byrne, 2001; Kline, 2015). Items were expected to present significant strong loadings ( $> .60$ ) to corroborate convergent validity (Brown, 2015), where a minimum of .40 for acceptance was established; otherwise, its exclusion was considered.

Internal consistency of the scales and their subscales was tested with inter-item correlations and Cronbach's alpha. To further support reliability, the Composite Reliability (CR) was calculated. Moreover, to test the sensibility of the ACQ-CMH factors (Calheiros et al., 2019), independent samples *t* test was analyzed for professional and housing status. Differences are expected among participants who are professionally committed when compared to those who are professionally inactive, as well as among participants who live in independent solutions versus those who live in group homes or with relatives.

To pursue a thorough analysis of the hypothesized ACQ-CMH-48 and its construct-related validity, discriminant and convergent validity were tested in diverse manners. First, to check the extent to which factors are distinct, discriminant validity of each factor was examined through the Average Variance Extracted (AVE). To provide evidence of discriminant validity, AVE for two factors should be greater than the square of the correlation between the two factors. Second, Spearman covariate correlations were applied to observe convergent and divergent validity of the AQC-CMH with other related constructs and measures. Positive and significant associations were expected with WHOQOL-Bref, RAS-P and BUES-P, while a negative correlation was expected with the K-6 distress scale.

For all analyses, an alpha level of .05 was used to determine statistical significance. Descriptive statistics, independent samples *t* test, and correlation between variables were completed through SPSS, version 24, while the CFA was performed through AMOS, version 24.

## Results

### Data Screening

No missing data within the ACQ-CMH to be validated were present. Sampling adequacy was confirmed by Kaiser-Meyer-Olkin (KMO) ( $p = .89$ ) and Bartlett's test of sphericity ( $p < .001$ ). Multivariate normality was confirmed, and all items were included in the absolute value of 2 for both skewness and kurtosis.

### The Hypothesized 6-Factor Model

To test the appropriateness of the six-factor and 48-item solution, as proposed by Sacchetto et al., et al. (2018), CFA was performed. Factors were allowed to correlate. The hypothesized model presented a poor fit:  $\chi^2(225) = 1609.35$ ,  $p < .001$ , CFI = .84, TLI = .84, and RMSEA = .051, 90% CI [.46, .56]. All items significantly loaded on their factors. The standardized factor loadings were all above .40, ranging from .41 to .75, except for item 44 (“ACQ44\_attend appointments regularly”), which presented a low regression weight (.35) and was therefore excluded. Some inter-factor correlations were high (range = .34 to .89), indicating the need for deeper examination. Discriminant validity of each factor was observed to identify limitations and solutions for a better model fit. Results on reliability, AVE, and inter-factor correlations were observed (Table 1). From the 15 possibilities of correlations between factors, four of them between the Practical Reason and other subscales of the ACQ-CMH were greater than the AVE for each factor, highlighting problematic discriminant validity. Hence, a revised model composed of five factors was considered, taking into account the theoretical framework and the dimensions of the ACQ-CMH as well.

### The Revised 5-Factor Model

Based on the evidence of discriminant validity, a revised five-factor model—called Model 2—was tested and compared to the six-factor hypothesized model. In fact, items of Practical Reason and Self-Sufficiency and Determination presented rather close contents. Indicators mostly report contents about independence, autonomy, and control, except for four items with contents including physical issues (e.g., “ACQ45\_be aware of my physical conditions”; “ACQ4\_have knowledge about healthy eating”). These four items were also less consistent, considering their factor loadings (below .40), and were therefore removed. Accordingly, the new factor was composed of 10 items and called Self-Determination and Control. The five-factor Model 2 presented a mediocre fit:  $\chi^2(225) = 1310.41$ ,  $p < .001$ , CFI = .87, TLI = .86, and RMSEA = .05, 90% CI [.44, .55]. However, it was better than the one

obtained by the six-factor Model 1. All items in Model 2 significantly loaded on their factors, ranging from .42 to .76. The majority of items presented standardized factor loadings of  $\geq .60$ , which suggests good convergent validity (Brown, 2015). However, the Optimism and Affiliation factors still presented a high correlation ( $r = .88$ ). Hence, a third model (Model 3) was tested, hypothesizing a second order factor for the two correlating dimensions. The model fit did not increase when compared with Model 2. Moreover, fit indexes for comparison ( $\chi^2$ ; ECVI; MECVI) indicated better fit for Model 2. Table 2 compares the fit statistics of the three measurement models tested in this study. Considering the goodness of fit results, as well as the consistency with the theoretical framework, the five-factor Model 2 has been identified as the better one to use with the psychometric study. Figure 1 displays the five-factor standardized Model 2 solution for the ACQ-CMH, the factor loadings of the items on each factor, and the correlations between factors. Model 2 is composed of a total of 43 items distributed throughout five dimensions, namely: Optimism (13 items); Affiliation (9 items); Activism (8 items); Self-Determination & Control (10 items); and Family (3 items).

Cronbach's alpha and Composite Reliability (CR) results of the 5-factor Model 2 are presented in Table 3. The overall scale showed high internal consistency (.94) and composite reliability (.96). Subscales also presented satisfactory results, ranging from .90 to .68 for alpha and .90 to .69 for CR. Corrected item-total correlations ranged from .31 to .69. Family revealed less reliability ( $\alpha = .68$ ; CR = .69), although it is still tolerable. The Self-Determination and Control ( $\alpha = .83$ ; CR = .83) of Model 2 presented better results than the Practical Reason ( $\alpha = .73$ ; CR = .73) and Self-Sufficiency and Determination ( $\alpha = .79$ ; CR = .80) of Model 1 (Table 1 and Table 3).

To analyze the sensibility of the five-factor ACQ-CMH, the differences in professional and housing statuses in ACQ-CMH factors were observed. Regarding the professional status or commitment (professionally active versus professionally inactive), an independent samples  $t$  test with the whole sample showed significant differences in Self-Determination and Control [ $t(223) = 4.74, p < .01$ ] and in Optimism [ $t(223) = 2.25, p < .05$ ]. Specifically, findings revealed that participants actively engaged in professional activities (employed, trainee, or volunteer) were rated on the ACQ-CMH as having more Self-determination and Control ( $M = 3.24, SD = 0.58$ ) than participants without a professional commitment ( $M = 2.75, SD = 0.67$ ). As for the housing status (independent living versus living with family or in group homes), significant differences were observed for Self-Determination and Control [ $t(223) = 4.8, p < .01$ ], as well as for Activism [ $t(223) = 2.01, p < .01$ ]. Accordingly, people who lived on their own were rated

at higher levels of Self-determination and Control ( $M = 3.17$ ,  $SD = 0.62$ ) and Activism ( $M = 2.22$ ,  $SD = 0.83$ ) than people living with relatives or in group homes ( $M = 1.99$ ,  $SD = 0.66$ ;  $M = 2.75$ ,  $SD = 0.79$ ).

To support construct-related validity, convergent and divergent validity were tested through bivariate correlations between the total scores of the ACQ-CMH, its five subscales (considering Model 2), and the other protocol measures. Results are shown in Table 4.

Strong estimate correlations were obtained among the overall ACQ-CMH and its subscales (range = .52 to .86). Convergent validity was supported by all the measures encompassed in the study protocol for this purpose, i.e., with RAS-P [ $r(208) = .41$ ,  $p < .01$ ], BUES-P [ $r(195) = .32$ ,  $p < .01$ ], and WHOQOL-Bref [ $r(171) = .51$ ,  $p < .01$ ]. Divergent validity was also confirmed by a negative and low correlation with the distress scale [ $r(197) = -.17$ ,  $p < .05$ ].

Regarding the new latent variable labeled Self-Determination and Control, it shows a strong connection to the overall ACQ-CMH [ $r(225) = .79$ ,  $p < .01$ ] and significant positive correlations with both the recovery [ $r(208) = .25$ ,  $p < .01$ ] and empowerment scales [ $r(195) = .21$ ,  $p < .01$ ].

Considering correlations between the other dimensions of the ACQ-CMH and the recovery, empowerment, and quality of life subscales, some relevant results are here reported. Significant strong correlation is evident between the Optimism factor and the RAS subscale of Personal Goals and Hope [ $r(210) = .48$ ,  $p < .01$ ]. However, the RAS Supportive Interpersonal Relationships subscale and the ACQ-CMH Family dimension are not highly related [ $r(209) = .16$ ,  $p < .05$ ], corroborating results of the exploratory study (Sacchetto et al., 2018). Regarding empowerment, the strongest correlations are observed between the subscales Self-Esteem and Efficacy [ $r(199) = .25$ ,  $p < .01$ ] and Optimism and Control over the Future [ $r(198) = .31$ ,  $p < .01$ ] with the Optimism dimension of the ACQ-CMH. Finally, correlations with the quality of life scale also show an adequate convergent validity; in particular, the Psychological Health subscale is strongly associated with Optimism [ $r(194) = .49$ ,  $p < .01$ ] and the Social Relationships subscale with the ACQ-CMH Affiliation [ $r(192) = .28$ ,  $p < .01$ ].

## Discussion

Given the scarcity of measures that take into account consumers' meanings of outcomes in mental health, this study aimed at presenting a consumer-valued research instrument, inspired

by Nussbaum's capabilities approach, for the evaluation of community mental health interventions. Thus, advancements on the validation study of the ACQ-CMH are reported. In particular, the appropriateness of the six-factor and 48-item solution obtained by the EFA study by Sacchetto et al. (2018)—identified in this study as the hypothesized model—was tested through CFA. This model structure revealed a poor fit within the present sample of community mental health consumers ( $n = 225$ ). Literature warns that follow-up studies often fail to confirm the model structures obtained by previous explorative studies through EFA (Van Prooijen & Van Der Kloot, 2001). Since EFA is a data-driven technique, fewer restrictions within the procedures than those for the CFA are required, for instance, regarding the number of factors to retain. Although the parallel analysis test (O'Connor, 2000) was applied in the EFA study for factor retention (Sacchetto et al., 2018), particular attention has been paid to the adequacy of the six latent variables of the hypothesized model (labeled Model 1) in this study. Therefore, an in-depth analysis of factors' discriminant validity was carried out, examining the extent to which they succeed or fall short in measuring theoretically different concepts. The observation of AVE of each latent variable and the square of the correlation between factors revealed scarce discriminant validity for the Practical Reason dimension which, in fact, displayed contents quite close to those of the Self-Sufficiency and Determination factor. Within the EFA study, authors had already remarked on this similarity, although some difference within the items was found out (Sacchetto et al., 2018). In this study, we tested a five-factor solution (identified as Model 2) combining these two close dimensions into one unique factor called Self-Determination and Control, which showed a better fit than the hypothesized Model 1. Ten items were retained for this new latent variable with significant standardized loadings above .40. Contents of these indicators consistently address individual autonomy and independence regarding housing, financial issues, mental health services, and medication, as well as with regard to relatives (e.g., "ACQ34\_have access to independent housing"; "ACQ21\_become financially autonomous"; "ACQ17\_ be autonomous regarding mental health services"; "ACQ27\_become independent from my family"). Self-determination and control concerning one's life and environment are clearly evoked within these items. Moreover, item 28 ("ACQ28\_have decision-making power over my life") directly refers to one's power and decision-making. People with mental health issues historically suffer a lack of self-determination, power, and control over their lives, as well as within the mental health system (Nelson et al., 2017). Accordingly, the latent factor Self-Determination and Control is particularly relevant for the group in the study. Theoretical coherence with recovery and empowerment—which are recognized as core models for orienting the mental health system (Corrigan, 2006; Davidson et al., 2009)—is also noticeable.

Supporting consumers in achieving their full capacity of self-determination and control over their life domains, as well as contributing to their empowerment and recovery processes, should be priorities in terms of service outcomes.

The five-factor Model 2 has been identified in the present paper as the better model solution, considering both psychometric and theoretical criteria. However, Optimism and Affiliation factors presented a high correlation. Therefore, a third model solution was tested through CFA—labeled Model 3—that embedded a second order factor for Optimism and Affiliation but did not present a better fit statistic (in particular, considering  $\chi^2$ , ECVI, and MECVI indices for comparison purposes) or a consistent theoretical interpretation, and it was therefore excluded. The correlation between Optimism and Affiliation in Model 2 may be interpreted through literature support. In-depth research about the meaning of quality of life for people with lived experience of mental health challenges reveals as crucial dimensions feelings of hope, belonging, and relationships (Connell et al., 2012; Connell et al., 2014; Gee et al., 2003). Relationships and sense of belonging are related to the experience of connectedness and of feeling accepted, which are comprised of social support, supportive relationships, and community integration. These elements are quite close to the Affiliation factor (e.g., “ACQ3\_feel respected by community members”; “ACQ16\_have feelings of belonging to the community”; “ACQ8\_feel integrated in the community”; “ACQ29\_have new relationships”). While hopefulness is linked to having goals and aspirations, including coping strategy, the abilities to make plans and to have purposes for the future (Gee et al., 2003) converge with Optimism (e.g., “ACQ31\_think about useful things for my life”; “ACQ30\_be optimistic”; “ACQ35\_enjoy my life more”; “ACQ2\_be hopeful about my future”). Therefore, a conceptual and theoretical distinction for optimism and affiliation is reasonable; future studies may elaborate on this relationship. Nussbaum states that *affiliation* and *practical reason* permeate all the others dimensions of her list (Nussbaum, 2000, 2017). Based on the results of our study, we propose that Optimism goes beyond Affiliation and Self-Determination and Control as the most relevant capabilities for people with mental illness experience.

Beyond adjusting the dimension of Self-determination and Control to identify a better model solution, findings of reliability and construct-related validity confirmed the adequacy of the dimensions and indicators of the five-factor ACQ-CMH, as well as its relevance for the community mental health context. Findings of convergent validity, i.e., significant bivariate correlations with quality of life, recovery, and empowerment measures, corroborate the supposed theoretical links with the ACQ-CMH. The link with empowerment was hypothesized

based on findings of the exploratory principal component analysis (Sacchetto et al., 2018). Therefore, an empowerment scale (ES) was added in the present study, endorsing convergent validity. Actually, the ES subscales of Self-Esteem and Efficacy and Optimism and Control over the Future showed a strong association with the ACQ-CMH Optimism factor. In fact, Optimism covers items concerning self-esteem, self-confidence, and hopefulness about the future (“ACQ48\_have self-esteem”; “ACQ40\_have self-confidence”; “ACQ14\_value my capacities”; “ACQ2\_be hopeful about my future”). The low association between RAS Supportive Interpersonal Relationships and ACQ-CMH Family was already observed in the exploratory study (Sacchetto et al., 2018) and reaffirms the existence of scarce support within the family. At the same time, an item of Self-Determination and Control indicates the need for the group in the study to become independent from their families (“ACQ27\_Become independent from my family”).

Moreover, the significant differences between groups in different conditions regarding their professional and housing statuses revealed an adequate sensibility of the ACQ-CMH factors. Higher rates of functional capabilities were found for people who were actively engaged in working activities and who were living independently. These findings meet the measure’s purpose and the theoretical basis of the capabilities framework, which advocates for socially valued roles and activities as well as agency and self-determination. The exploratory study had already suggested individual independence in terms of employment and housing as crucial vehicles for the achievement of capabilities (Sacchetto et al., 2018). Future studies may afford a comparison within groups to further confirm the effect of programs such as independent housing and supported employment. The findings may serve as recommendations for effective interventions for the promotion of capabilities.

By advancing psychometric analysis for the ACQ-CMH, we aimed to provide a new evaluative measure for community mental health programs that may assess its results (and plan its intervention) based on the achievement of consumers’ capabilities. This is particularly required considering that even though there have been advancements in the deinstitutionalization process, the psychiatric and institutional perspectives still dominate the psychosocial initiatives within the community mental health system, which is still focused on illness-centered interventions and evaluation (Jorge-Monteiro & Ornelas, 2016). In this sense, capabilities-oriented measures are recommended for a transformative shift (Ornelas et al., 2019). The ACQ-CMH addresses this goal, offering a consumer-valued framework with

specific dimensions and indicators of capabilities to be used in a routine service evaluation setting.

The study presents some limitations. For the data collection, a large sample size, as expected for the confirmatory analysis, was not achieved. However, all consumers available at the time participated in the collection of the data. In-depth analysis of the factorial structure was conducted, including CFA, and other psychometric characteristics were reported, including reliability, sensibility, and construct-related validity. Follow-up studies may elaborate on the validation process for the measure of robustness. In particular, other psychometric properties may be analyzed, such as responsiveness, predictive validity, and sensitivity to change. Repeated data collection may be applied in order to observe variability of results depending on time differences (for instance, baseline and six-month follow up).

Finally, pre-established international partnerships were retained. The ACQ-CMH was already translated into the Italian language through a cross-cultural adaptation process (Beaton et al., 2000), and data collection is ongoing (n = 98) for a national validation of the Italian version of the ACQ-CMH. Meanwhile, a partnership with a North-American research group is revising the English version of the measure to start transnational research. Hence, we expect to obtain a well-established and multi-language questionnaire inspired by the capabilities approach that facilitates comparative international data, contributing to a transformative change in community mental health.

The ACQ-CMH aims at supporting service outcomes evaluation, measuring consumers' achievements obtained through their participation in community mental health services. We expect that repeated measurements within time intervals in services' routine practices may help mental health professionals to look at consumers' gains in capabilities. Consequently, a more efficient intervention may be planned in order to increase individual potential, improving both the services' response and consumers' quality of life.



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Table 1

*Reliability and discriminant validity of the 6-factor model of the ACQ-CMH.*

	$\alpha$	CR	1	2	3	4	5	6
Optimism (1)	.90	.90	<b>.41</b>					
Affiliation (2)	.83	.83	.78	<b>.36</b>				
Activism (3)	.84	.84	.17*	.21*	<b>.41</b>			
Practical Reason (4)	.73	.73	.63	.56	.18*	<b>.26</b>		
Self-Suff-Determination (5)	.79	.80	.31*	.24	.40*	.44	<b>.37</b>	
Family (6)	.68	.69	.29*	.16*	.15*	.29	.11*	<b>.44</b>

*Note.* Diagonal numbers in bold represent average variance extracted. Numbers outside the diagonal represent square inter-factor correlations. CR = Composite Reliability.

\*indicates evidence of discriminant validity.

Table 2

*Goodness of fit statistics for the three measurement models.*

	$\chi^2$	$\chi^2/df$	CFI	TLI	RMSEA	ECVI	MECVI
6-factor Model 1	1609.35	1.59	.84	.84	.51	8.2	8.48
5-factor Model 2	1310.41	1.55	.87	.86	.50	6.75	6.69
5-factor + 2 <sup>nd</sup> order factor Model 3	1317.77	1.55	.87	.86	.50	6.77	6.98

Table 3

*Reliability for the 5-factor model of the ACQ-CMH.*

Scale	N° of items	$\alpha$	CR
ACQ-CMH overall	43	.94	.96
ACQ-CMH_Optimism	13	.90	.90
ACQ-CMH_Affiliation	9	.83	.83
ACQ-CMH_Activism	8	.84	.84
ACQ-CMH_Self-Determination & Control	10	.83	.83
ACQ-CMH_Family	3	.68	.69

*Note.* CR = Composite Reliability.

Table 4

*Pearson correlations of the 5-factor ACQ-CMH with its subscales, WHOQOL-Bref, RAS-P, BUES-P, K6*

Scale	ACQ-CMH	ACQ1	ACQ2	ACQ3	ACQ4	ACQ5
ACQ-CMH						
ACQ1. Optimism	.86					
ACQ2. Affiliation	.81	.78				
ACQ3. Activism	.69	.37	.38			
ACQ4. Self-Determ&Control	.79	.53	.48	.54		
ACQ5. Family	.52	.43	.34	.28	.29	
WHOQOL-Bref	.51	.55	.43	.23	.33	.28
RAS-P	.41	.48	.36	.17 <sup>a</sup>	.25	.19 <sup>a</sup>
BUES-P	.32	.35	.22	.22	.21	.12 <sup>b</sup>
K6	-.19	-.27	-.17 <sup>a</sup>	-.06 <sup>b</sup>	-.11 <sup>b</sup>	-.02 <sup>b</sup>

*Note.* Correlations are significant at  $p < .01$  level, with the exceptions given in the footnotes.

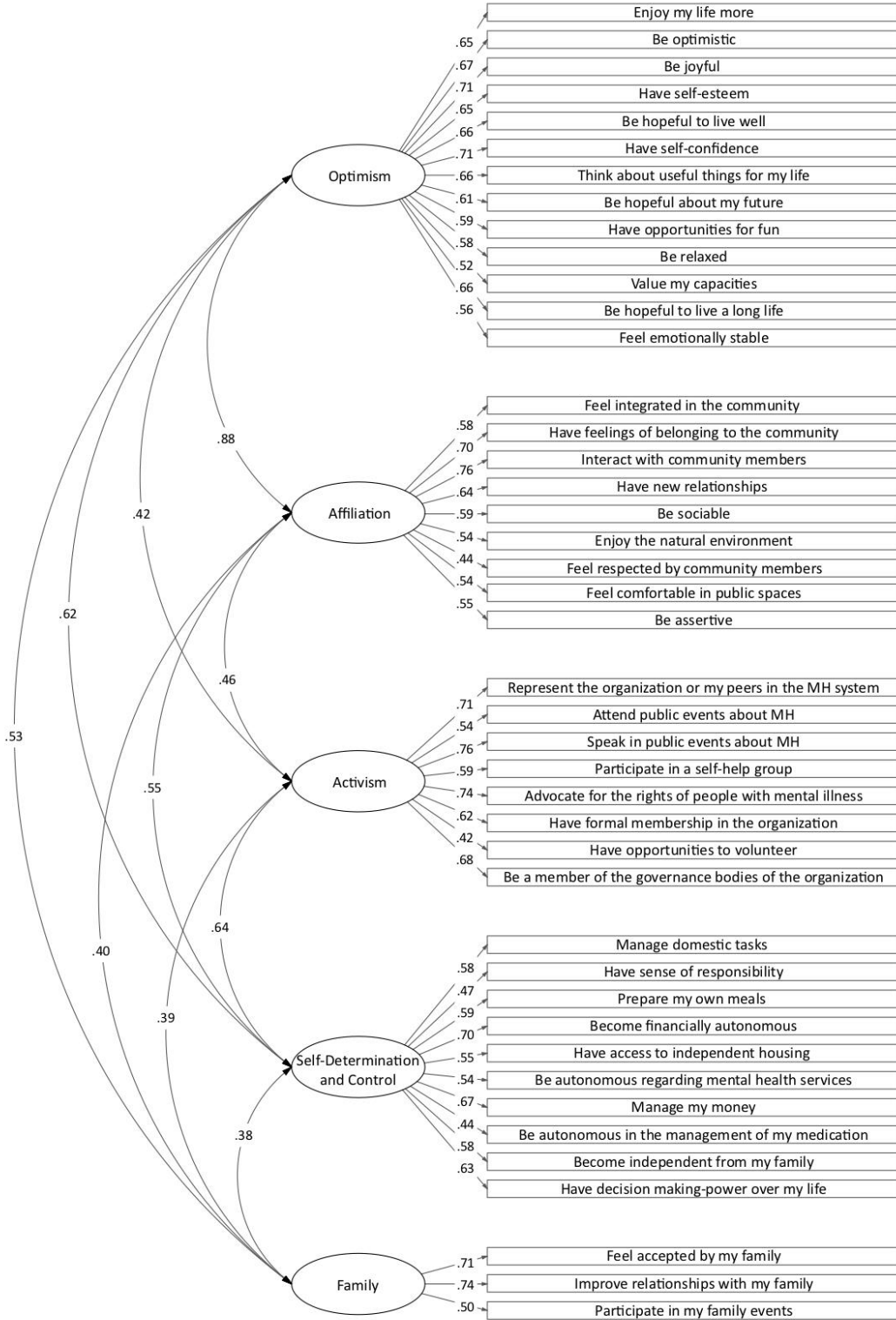
ACQ-CMH = Achieved Capabilities Questionnaire for Community Mental Health; WHOQOL-Bref = World Health Organization Quality of Life Bref; RAS-P = Portuguese version of the Recovery Assessment Scale; BUES-P = Portuguese version of the Empowerment Scale; and K6 = Distress Scale.

<sup>a</sup> Significant at  $p < .05$  level    <sup>b</sup> Not significant at  $p < .05$



**Figure 1**

*Confirmatory Factor Analysis of the 5-factor ACQ-CMH*





**GENERAL CONCLUSIONS**



## 1. Main Results

### 1.1. Collaborative processes

Collaboration and participation have been applied throughout the research work, particularly within the measure development (Study 1) and the assessment of the content validity (Study 2). The application of these community psychology core values, also consistent with the capabilities framework, has allowed the promotion of a collaborative and empowering relationship between academics and community members. At the same time, traditional research roles were transformed, through a process of sharing power and control among the research tasks (Sacchetto et al., 2016; Sacchetto et al. 2018). In particular, the constitution of specific structures, namely a steering committee within the first study and a panel of experts for the content validity, ensured consumers' engagement with a decisive role of influencing. These structures worked like spaces of dialogue, mutual trust and respect, where negotiation and consensus occurred, always privileging consumers' meanings and understanding. Each member contributed with competencies, skills and resources, fostering a process of mutual learning and co-empowerment. In this sense, the diversity of knowledge and expertise was celebrated. Theoretical and technological resources were shared, for instance, the training session about Nussbaum capabilities framework within the study for the measure construction was an opportunity of learning. Finally, success opportunities were shared (Suarez-Balcazar, 2004), particularly, the first paper about the collaborative construction of the measure published in the *Psychiatric Rehabilitation Journal* involves all the members of the steering committee in the authorship. Some testimonies of consumers that composed the steering committee are reported in Sacchetto et al. (2016), showing individual feelings of empowerment.

Concretely, the ACQ-CMH has suffered significant modifications based on the results of the collaborative process. During the work of the steering committee for the data analysis and items generation (Study 1 – 2<sup>nd</sup> and 3<sup>rd</sup> phases), consumers and researchers often did not interpret the data in the same way (Sacchetto et al. 2016). The involvement of consumers ensured the interpretation of the focus group data, the selection of the most relevant indicators, and the formulation of the items. The same has occurred during the assessment of the content validity within second study. The phrasing has been adjusted basing on consumers suggestions, to guarantee a more comprehensible language for the target population. At all, 29 items were modified considering consumers rating and proposals (Sacchetto et al., 2018). This evidence

supports the idea that the perspective of the group in study always deserves particular attention, since it reflects the understanding and meaning of whom lives the direct experience.

In this sense, the participative procedures allowed to obtain ecologically valid outputs, i.e. really relevant for the local community (Christens & Perkins, 2008). That way, collaboration has confirmed its relevance through the promotion of the ecological validity of the produced knowledge (Kelly, 2006). Moreover, this PhD work applied collaboration for evaluation purposes, in line with recommendation for mental health research, which suggest consumers' participation in the definition of needs and expectations for program evaluation, once professionals may not have the same understanding of programs objectives and outcomes (Telford & Faulkner, 2004).

Finally, the self-administration way to fulfill the questionnaire, intentionally chosen to promote self-controlled and empowering processes, represented a concrete opportunity for consumers to reflect and assess their paths within the mental health programs. Scientific evidence indicates that self-evaluation through the use of self-reported measures reduces dependency on professionals and promotes users' empowerment (Minkler & Wallerstein, 2011).

## **1.2. The ACQ-CMH**

One of the most relevant result of the present PhD thesis is the identification of a new framework and measure for community mental health inspired by the capabilities approach, in line with community psychology principles and values. This output, which responds to the main goal of the research work, is a contribution for advancements in community mental health, providing a concrete guidance that may be applied for a transformative change. The ACQ-CMH is composed by dimensions and indicators that reflect consumers' interests and preferences of gains and goals that may be considered basic criteria for orienting community mental health intervention and evaluation.

The present research also provides a theoretical contribution, applying and adapting the innovative framework of the capabilities approach, which stems from a scientific area that is not related to mental health (Nussbaum & Sen, 1993). The capabilities approach, focusing on individuals' choices and preferences for quality of life evaluation, represents a radical counterpoint to the general tendency of providing pre-established responses within the mental health system, and fosters a paradigm shift prioritizing "beneficiaries" decision-making power. Agent's perspective is at the center instead of clinical criteria defined by professionals.

The deep analysis of the capabilities framework with the strict collaboration of people with mental illness experience offers a cultural adaptation of Nussbaum's capabilities account and its list of 10 dimensions. The first paper of the present PhD work presents a specific output, namely a review of Nussbaum's definitions of the ten capabilities basing on consumers meanings and experiences, elaborated by the steering committee (see Article I - Appendix). In the following studies, the ten capabilities as listed and defined in the theoretical model, were reorganized and reduced, based on the results of the exploratory and confirmatory factor analysis, revealing more context-specific dimensions and indicators of capabilities for the population in study. Throughout the diverse research studies great refinement and reduction of the measure have been achieved. The first version of the ACQ-CMH, after the collaborative process for the measure development, was composed of 104 items ordered by the ten theoretical dimensions of capabilities (Sacchetto et al., 2016). Then, through a collaborative process for the assessment of the content validity, a 98-item version has been proposed. The following quantitative studies, with independent samples, have pursued a more precise and adequate version, considering both the ecological and the psychometric properties.

Specifically, the exploratory factor analysis and the psychometric examination within Study 3 have revealed good outputs. Reliability through test-retest ( $n = 33$ ) within 2 weeks presented acceptable psychometric properties, except for three items that showed low results in reliability coefficient ( $<.6$ ), as well as significant difference between T1 and T2 applications (ANOVA,  $p < .05$ ), and were therefore removed for further analysis. Five more items were eliminated before EFA, because of a high rating of not applicable responses (about one third of the sample). The parallel analysis test and the exploratory principal component analysis (EPCA) showed a six-factor structure with 48 items that explains 48.88% of the total variance ( $KMO = 0.89$ ; Bartlett  $p = .00$ ). The dimensions of the six-factor structure are: "Optimism" (13 items;  $\alpha = .91$ ), "Affiliation" (9 items,  $\alpha = .84$ ), "Activism" (8 items,  $\alpha = .84$ ), "Practical Reason" (8 items,  $\alpha = .76$ ), "Self-Sufficiency & Determination" (7 items,  $\alpha = .76$ ), and "Family" (3 items,  $\alpha = .78$ ). Convergent validity was supported by a significant strong correlation with the quality of life measure ( $r(129) = .60$ ,  $p < .001$ ) and by a significant moderate correlation with the recovery scale ( $r(92) = .46$ ,  $p < .001$ ). Discriminant validity was also confirmed by a low negative correlation with the K6 distress measure ( $r(139) = -.17$ ,  $p = .046$ ). Sacchetto et al. (2018) report in detail the findings of this research stage.

The confirmatory study (CFA) has allowed a further refinement of the ACQ-CMH measure. Within this last study, the appropriateness of the six-factor and 48 items solution obtained in the previous study was tested, showing a poor fit ( $\chi^2(225) = 1609.35$ ,  $p < .001$ , CFI

= .84, TLI = .84, and RMSEA = .051, 90% CI [.46, .56]). Therefore, discriminant validity of each factor was examined and problematic results for the dimension of “Practical Reason” have been observed. Moreover, this component presented four items with low factor loadings (below .40), while the remaining three indicators were quite close to the contents of the “Self-Sufficiency and Determination” factor, being related to control and autonomy issues. Therefore, a new dimension called “Self-Determination and Control” was proposed, composed of a blend of ten items (three from the previous “Practical Reason” subscale and seven from the “Self-Sufficiency and Determination” dimension). The new five-factor and 43 items model (called Model 2) was then checked, showing mediocre goodness-of-fit statistics ( $\chi^2(225) = 1310.41$ ,  $p < .001$ , CFI = .87, TLI = .86, and RMSEA = .05, 90% CI [.44, .55]). Hence, a third model was evaluated with a second order factor for two high correlating dimensions, namely “Optimism” and “Affiliation” ( $r = .88$ ), but did not show better results than Model 2. Outputs of this last research study are described in detail in the third submitted article (Sacchetto et al, Submitted). So, the final version of the ACQ-CMH proposed by this research work, is a five-factor solution and 43 items (ACQ-CMH-43). The five dimensions are “Optimism” (13 items;  $\alpha = .94$ ), “Affiliation” (9 items;  $\alpha = .83$ ), “Activism” (8 items;  $\alpha = .4$ ), “Self-Determination and Control” (10 items;  $\alpha = .83$ ) and “Family” (3 items;  $\alpha = .68$ ). Convergent validity of this model was confirmed by positive significant correlations with all the scales used for the purpose, namely with the recovery RAS-P [ $r(208) = .41$ ,  $p < .01$ ], the empowerment BUES-P [ $r(195) = .32$ ,  $p < .01$ ], and the quality of life WHOQOL-Bref [ $r(171) = .51$ ,  $p < .01$ ]. A negative and low correlation with the distress scale [ $r(197) = -.17$ ,  $p < .05$ ] also supported the thesis of discriminant validity.

“Optimism”, which is the first and biggest component of the measure, is quite related to recovery, recalling hopefulness and self-confidence (Corrigan et al., 2004). Other items reflect self-efficacy and motivation that link to psychological empowerment (Zimmermann, 2000) and Nussbaum dimension about *emotions*. Although this big component composed of thirteen items shows some psychometric limitation (i.e. high correlation with “Affiliation”), it has maintained its structure in both empirical studies, namely exploratory and confirmatory factor analysis. These results lead to a possible explanation, in line with the literature: recovery and empowerment are interconnected processes, moreover, individual’s empowerment is considered a component or a moderator of the personal recovery process (Brown, 2012; Ralph, 2000). That way, it seems reasonable to have recovery and empowerment elements embedded in a subscale. Besides, “Optimism” also encompasses indicators about longevity and joyful life,



which seem quite consistent with feelings of hope and future perspectives and recall Nussbaum's dimensions of "life" and "play".

The second subscale of 9 items is called "Affiliation". The same label of the seventh dimension of Nussbaum's capabilities list has been used, considering the match between the author definition and the obtained dimension. It advocates for the need of social connectedness and effective community integration (Nelson et al., 2017), recalling core values for community mental health within a community psychology perspective. The psychometric analysis has indicated other elements within this dimension, such as the relation with the natural environment and the public spaces. People with mental health problems do value a comfortable, respectful and enjoyable relationship with the environment, evoking Nussbaum dimension of "other species".

The third dimension "Activism" and its eight items, recall for Nussbaum's political aspect of the "control over one's environment", and remind a crucial issue for people with mental illness experience, which is the exercise of civil and political rights. Context-specific items about peer support and mutual aid have also emerged in this dimension. In fact, initiatives of advocacy and peer-support alternatives have multi-level relevant impacts: at the individual level, to strengthen empowerment and recovery; at the institutional and political level to influence the mental health system and social policy (Munn-Giddings & Borkman, 2017; Stratford et al., 2017).

The "Self-Determination and Control" dimension, comprising ten items, recalls Nussbaum's dimension of "practical reason", with contents of critical reflection and life planning. This dimension also reveals aspects of individual responsibility, independence and control regarding daily life, including mental health care, linking to the material aspect of Nussbaum's capability of "control over one's environment".

The last subscale, "Family", is a 3-items component and represents a specific aspect of the broader capability of "affiliation". For the population in study, this dimension has to be interpreted considering some evidence in the literature about experience of discrimination and lack of support within the family (Hamilton et al., 2016). Accordingly, a significant weak relation between Family and the recovery dimension of Supportive Interpersonal Relationships was observed in this PhD work (Sacchetto et al., 2018). Indeed, the indicators of this last subscale consist in consumers' desires of acceptance, participation and improvements in familiar relationships.

### **1.3. The association between capabilities and independent housing and employment**

Considering the exploratory aim of observing housing and working impacts in capabilities, the present research revealed some initial evidence of a positive association between some capabilities and independent housing and employment. Specifically, the exploratory study identifies a significant positive correlation between the Self-Determination dimension and independent housing (i.e. respondents that were living on their own) (Sacchetto et al., 2018). The last confirmatory research stage develops this hypothesis, analyzing the sensibility of the ACQ-CMH factors (Calheiros et al., 2019) through independent samples *t* test considering respondents' professional and housing status. Statistically significant differences have been found in "Optimism" and "Self-Determination and Control" dimensions, when comparing professionally active respondents with professionally inactive ones. Specifically, findings revealed that participants actively engaged in job activities (e.g. employed, trainee, or volunteer) in the competitive labor market, were rated on the ACQ-CMH as having more "Self-determination and Control" and "Optimism" than participants without a professional commitment. Moreover, the *t* test for the housing status (independent living versus living with family or in group homes) showed significant differences for "Self-Determination and Control", as well as for "Activism". Accordingly, people who lived on their own were rated at higher levels of "Self-determination and Control" and "Activism" than people living with relatives or in group homes. These results are in line with the evidence of international and national studies, which have found a positive correlation between supported employment and independent housing in both empowerment and recovery outputs (Dunn et al., 2008; Sá-Fernandes et al., 2018; Wong & Solomon, 2002).

### **1.4. Cross-cultural adaptation and translation**

The present PhD work focuses on the development and validation of the ACQ-CMH at a national level, seeking the identification of psychometric properties and a robust structure of the Portuguese version of the measure. In parallel, as secondary research goal, a process of cross-cultural translation and adaptation of the measure has been pursued. Therefore, an international partnership has been established with two community psychology scholars, namely Professor Marta Elena of the Catholic University in Milan, Italy (Università Cattolica del Sacro Cuore di Milano) and Professor Bret Kloos of the University of South Carolina in Columbia, North American. Both the Italian and English versions have been obtained through

a procedure of translation and back translation (Beaton et al., 2000), involving mother tongue academics and service providers within the community mental health field. The Italian translation of the 48-item version of the measure, called ACQ-CMH-48-IT (Annex XII), has already been applied to a national sample of consumers of six different community and recovery-oriented services in three Italian cities ( $n=100$ ), namely four programs in Milan, one in Modena and one in Aquila, to begin a psychometric exploration. Respondents were aged between 19 and 76 years ( $M = 45$ ;  $SD = 12$ , 43). The majority were male (54%), single (78%), living with relatives (45%) or in group homes (23%). Only the 38% had completed high school, while almost the half of the sample was unemployed (48%). The most frequent reported diagnosis were schizophrenia (19%) and major depression (10%) and hospitalization ranged between 0 and 22 times ( $M = 3$ , 16;  $SD = 4$ , 9). Specifically, internal consistency through Cronbach alpha, and correlational outputs for convergent and discriminant validities with Italian versions of the recovery (Basso et al., 2016), quality of life (De Girolamo et al., 2000) and distress (Kessler et al., 2002) scales, were already observed. The Italian version of the ACQ-CMH-48 has revealed some preliminary good results of psychometric qualities, quite consistent with the Portuguese one. The six subscales have showed good internal consistency through Cronbach alpha in the Italian sample (Optimism  $\alpha = .91$ ; Affiliation  $\alpha = .85$ ; Activism  $\alpha = .79$ ; Practical Reason  $\alpha = .81$ ; Self-Determination and Sufficiency  $\alpha = .84$ ; Family  $\alpha = .79$ ), while convergent validity has been confirmed by a significant positive correlation with both the quality of life measure (WHOQOL-Bref) ( $r = .59$ ,  $p < .01$ ) and the recovery scale (RAS-IT) ( $r = .69$ ,  $p < .01$ ). Whereas, the distress measure (K6) corroborates the discriminant validity with a significant negative association with the ACQ-CMH-48-IT ( $r = -.55$ ,  $p < 0.01$ ). The Italian data collection and analysis have been developed by two Master degree students of the Catholic University in Milan (IT), with the supervision of Professor Marta Elena and in partnership with the PhD student. Procedures and results of this empirical study are reported in detail in their Master Thesis (Zaninetta & Marta, 2018; Pieri & Marta, 2019).

## 2. Limitation of the Study

The PhD work has some limitations. First of all, the size of the samples for the quantitative studies (EFA and CFA), although they are still considered an acceptable minimum (Guadagnoli & Velicer, 1988). Furthermore, the two convenience samples were composed of

all consumers available at time. Some difficulties have emerged for the data gathering, precluding the possibility of a representative sample of the population. For instance, to reach potential respondents, invitation letters have been sent to community programs, which sometimes did not respond at all, or took long time to respond. Besides, respondents lasted around one hour and a half on average to complete the overall protocol for the data collection. Two factors have influenced the long duration of each application, namely the length of the protocol, and respondents' literacy issues. Regarding the length of the ACQ-CMH, great refinement and reduction of the measure have been achieved among the research work. For literacy issues, only the half of both quantitative samples had completed high school education at time of data collection. Therefore, assistance during the protocol fulfillment have been provided if requested (62% of the sample in Study 3 and 41% of the sample in Study 4 asked for assistance), to ensure quality and fidelity of the collected data.

The ACQ-CMH is a new developed measure, therefore follow-up quantitative data collection and analysis are required to obtain a well-established version. The five-factor and 43 items model proposed within the last confirmatory study, suffered a modification of the factorial structure comparing with EFA results, namely the dimensions were reduced from six to five subscales. This modification has been obtained following in-depth analysis, such as factors' discriminant validity (Sacchetto et al., Submitted). Goodness of fit outputs of the final model were acceptable, but further studies may seek to confirm the five-factor and 43 items solution with evidence of good indices.

The measure is quite context-specific. On one hand, it reveals a high cultural sensitivity and ecological validity for the group in study, on the other, it may interfere with the generalizability to other study groups with different experiences or social conditions. To overcome this issue, Sacchetto et al. (2018) recommend an initial step of measure adaptation through participatory procedures with members of the specific target group. Inclusively, an adaptation of the ACQ-CMH measure for the population of people with lived experience of homelessness has been already developed with participative methods. Three focus group sessions with participants of the housing first program in Lisbon have been organized to adjust the relevance and adequacy of the items (Bonifácio & Ornelas, 2017). As a result, a specific measure for this target group, has emerged and used in a larger project called *Homelessness as Unfairness*, or HOME\_EU, and supported by the European Commission (registration number: H2020-SC6-REVINEQUAL-2016/GA726997). Specifically, the adapted measure composed

of 54 items, was embedded in the survey protocol for service users, to compare housing first and traditional homeless service users in eight European countries (Greenwood et al., 2020).

Another limitation of the study may be pointed to the choice of focusing on achieved capabilities instead of opportunities or possibilities (i.e. capabilities themselves). In the capabilities literature there is a large discussion about how capabilities should be measured (Alkire, 2002; Hopper, 2007; Robeyns, 2005). Within the present research, we opt to analyze consumers' achieved capabilities, which are called also as "functionings". That way, the innovation is placed on the process of evaluation that assess the extent to which programs and services are supporting goals and achievements as defined by consumers, and not by professionals. By carrying out this work, we tried to apply the core thesis of the capabilities approach, that is, building on doings and beings people value (Sen, 2004).

The ACQ-CMH rating scale of response has revealed some limitations, especially during the psychometric analysis of the measure. In the collaborative analysis of the content validity, the panel of evaluators, composed by consumers, professionals and researchers, proposed to use a 4-point rating scale (*4 = totally achieved; 3 = partially achieved; 2 = not much achieved; 1 = not achieved at all*), plus a *not applicable* option, in order to provide the possibility to rate only capabilities valued by respondents. This choice generated some difficulties within the exploratory analysis that have been overcome applying and comparing different statistical approaches (Sacchetto et al., 2018). Thus, in the following confirmatory study, the *not applicable* option has been avoided; respondents not interested in a specific gain of capabilities were suggested to respond with *not achieved at all*. In fact, what is useful for programs evaluation, is to observe ratings within the capabilities dimensions, in order to supervise and adjust the support provided to consumers within a program routine. Low ratings on capabilities may suggest a further collaborative analysis with consumers, to better understand if people are not interested in a specific capability gain, or if they were not supported enough.

### **3. Implication for the Practice**

Multi-level implications for the practice stemming from the present research work may be identified, encompassing recommendations for evaluation processes, policy guidelines and programs orientation, as well as professional attitudes.

Regarding evaluation, approaches based on the identification and assessment of the needs of the group in study are recommended for service planning and delivery. The design of programs and services need to be determined by the effective requirements of their users (user-centered), and not merely by their nature (service-centered) (Petersen & Alexander, 2001). A program outcome has to reflect expected gains and goals of the target group. Participatory procedures to capture the real significances of these needs and expectations are required, ensuring that the validity, usefulness and sustainability of the produced knowledge (Trickett & Espino, 2004). Given the scarcity of measures that consider consumers' meanings of outcome in mental health, consumer-based research instruments are here considered a crucial contribution for the evaluation of community mental health interventions. Even more because of the actual diversity of community mental health models, the impacts of interventions on individual outcomes have to be examined through participatory processes to find out best practices (Ornelas et al., 2019).

The adaptation of Nussbaum's capabilities framework (Nussbaum, 2000) proposed by this PhD thesis resulted in an ecological multi-dimensional and multi-level model that takes into account personal, interpersonal, social, organizational and political elements. This account may provide policy recommendations for mental health, claiming for the promotion of complex capabilities, as the exercise of practical reason, affiliation and control, beyond primary goods, such as material and cultural necessities. For instance, public policy may promulgate decision-making processes and structures within the mental health system to enable consumers' to exercise their right of effective participation and influence. Moreover, concrete guidelines for the orientation of community mental health programs and services may be outlined by policy makers. The ACQ-CMH suggests some specific dimensions and indicators that may be embedded in the intervention models to enhance the achievement of capabilities and quality of life. For instance, the first two dimensions of the measure ("Optimism" and "Affiliation"), highlight the need to promote responses that allow a long-term perspective of optimism and hopefulness, through activities and roles that promote social commitments, membership and sense of belonging to the community. Individual feelings of acceptance and respect within social ties, beyond self-esteem and self-confidence, are relevant dimensions for emotional well-being. Willingness of new social interactions and relationships, as well as improvements of familiar relations (specifically referred within the "Family" dimension), have also emerged as relevant components of consumers' quality of life. Moreover, leisure and connection with the nature are consumer-valued elements, in order to feel joyful, comfortable and relaxed. The

“Activism” dimension, with contents of political participation in social policy and practice, highlight the need to provide opportunities for the exercise of formal roles for governance. A concrete way to get consumers participation in service planning, delivery and evaluation, is promoting their membership on the board director of the program. Moreover, the opportunity for valued role structure is an endorsed feature for organizational empowerment (Maton, 2008), and it is also recommended for community mental health organizations within national studies (Jorge-Monteiro & Ornelas, 2014). At the same time, opportunities for consumer-led and peer support initiatives may be provided, as well as advocacy actions to fight for civic, social, professional and educational rights (Munn-Giddings & Borkman, 2017). Finally, the “Self-Determination and Control” subscale of the ACQ-CMH, evokes the requirement of agent-centered empowering approaches. Consumers seek for decision-making power and refer their willingness to be autonomous in managing and controlling their paths, giving concrete examples of everyday life, like domestic tasks, medication and financial issues. Additionally, they express desires of independent housing and incomes access, and clearly ask for independence regarding their families and mental health services, which traditionally have promoted relations of dependency and misbalanced power.

Beyond the lack of social and political arrangements, along with concrete guidelines to support community mental health programs, the professional resistance to act a paradigm shift in the community mental health system seems to be a major barrier (Ochocka et al., 2002). In this sense, some recommendations in terms of professional attitudes and ethics are here provided. Community mental health practitioners, as service providers, often still appeal institutional and clinical models to define their practice. Intervention models based on the medical paradigm have implications in the professional rational, including beliefs, values, language, terminology, and power position. Until people with mental illness experience are seen as pathological individuals, they are stripped out of their social contexts and consequently, responses will be planned based on individuals’ limitations. A social model of mental health is required (Wallcraft & Hopper, 2015) to switch the focus from individual problems to structural lacks (e.g. political an institutional) that causes social suffering. The capabilities approach and community psychology accounts share a societal perspective and common values on human being and wellness, recognizing internal capacities in everyone, and addressing favorable contextual opportunities for the development of individual’s potential. So, the professional-centered intervention that seek to redeem people’s deficit and to evaluate the "adequate" responses, should be replaced with a capabilities-oriented and agent-centered model. People

should have the opportunity to decide on social roles and activities within a bunch of options, and service providers should support the act of free choice and accomplishment. A transformation of the community mental health system should consist in overcoming pre-established programs within artificial settings that perpetuate segregation, avoiding the illness-oriented vision of cure through trainings for a supposed “readiness” for integration. To achieve this purpose, professionals of the community mental health field should leave behind the privilege position of expert and provide opportunities of sharing power, knowledge, responsibilities and resources, celebrating the diversity of backgrounds within a collaborative partnership (Suarez-Balcazar et al., 2004). More equal and balanced relations based on a collaborative approach are needed, which contribute at the same time to foster consumers’ self-determination, empowerment and recovery (Piat & Polvere, 2014). Finally, community psychologists are called to contribute to this effort, since their models and values are quite coherent and favorable to enact a transformative shift.

#### **4. Future Studies**

The present PhD work has gone through several analysis to pursue a well-established measure, such as face and content validity, reliability, factorial validity (EFA and CFA), factor sensibility, and construct-related validities (convergent and discriminant). Follow-up studies may advance the psychometric qualities of the ACQ-CMH, embedding the examination of other properties, like responsiveness, sensitivity to change and predictive validity. Besides, future analysis may focus on the effect of different models of intervention in community mental health in terms of better achievement of capabilities. Specially, a comparative study of programs based on a “stair-case model”, such as sheltered employment within protected environments, with “intervention-first model”, like supported employment or independent housing with flexible and individualized facilities, may be of further interest. The idea is that independent housing and supported employment seem to be the most adequate responses in line with the capabilities theory (Ornelas et al., 2019), since they provide diversified and adaptive services based on consumers’ choices and interests, and lead to positive findings on self-confidence, respect of others, personal income and community integration (Drake & Wallach, 2020; Wong & Solomon, 2002). Future studies may confirm this hypothesis.



Further research may seek to evaluate also the extent to which a program enhances potential capabilities for its participants. In this sense, the average level and the range of different achievements obtained by ACQ-CMH may be analyzed, to capture program's ability to promote opportunities and freedom to be and to do (i.e. capabilities themselves). The variation in achievements may be calculated through a metric (namely a modification of a standard entropy measure from information theory), which is independent of program size. Sacchetto et al. (2018) elucidate this proposal. To achieve a major comprehension of capabilities in terms of potential opportunities or range of realistic possibilities, qualitative methods like in-depth interviews may be also applied. A multi-method analysis may offer a more exhaustive picture and understanding of consumers' needs, expectation, goals and gains, as well as of the role of social programs of support, in order to check the matching between consumers' perspective and program response. This multi-level effort of analysis and evaluation may strength the bonds between systems and individuals. Finally, longitudinal studies with repeated ACQ-CMH application, may provide crucial new information to observe individual paths of capabilities over time.

Two recent literature reviews about capabilities measurement in health have comprised the ACQ-CMH in its systematic analysis (Helter et al., 2020; Till et al., Under Review). These systematic reviews recognize the relevance and adequacy of the instrument developed within this PhD work, especially regarding the innovation of a consumer-based and collaborative approach for the measure development. The promotion of scientific advances, corroborate the willingness to persist in researching on the ACQ-CMH, so that it may contribute to improve both community mental health responses, as well as consumers' quality of life.

The measure has been already translated into the English and Italian languages. Italian data collection is already started and planned to proceed for a national validation of the ACQ-CMH-IT, while for the English version, a data collection is in forecast. Thus, further studies will carry on the persecution of a well-established and multi-language measure to foster the comparison of multi-site data, basing on a capabilities framework for transformative change.

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**ANNEXES**





**Annex I - Proceedings of the 3rd Congress of the Order of Portuguese Psychologists**



**ANNEXES**



**Annex I - Proceedings of the 3rd Congress of the Order of Portuguese Psychologists**





## A Psicologia Comunitária e a Abordagem das Capacidades

Beatrice Sacchetto<sup>1</sup>; José Ornelas<sup>1</sup>; Manuela Calheiros<sup>2</sup>

*1. ISPA-Instituto Universitário, Lisboa, Portugal*

*2. CIS-IUL Research Center, ISCTE- Instituto Universitário de Lisboa, Portugal e  
Centro de Investigação em Ciência Psicológica, Faculdade de Psicologia, Universidade de Lisboa, Portugal.*

### Resumo

A abordagem das capacidades emerge como um indicador alternativo na área da economia e do desenvolvimento e foi adoptada em estudos sobre a qualidade de vida das populações vulneráveis. As capacidades são essencialmente liberdades de escolha e de agência: a promoção das mesmas é determinada também pelo contexto político, social e institucional. A autora Martha Nussbaum elaborou uma lista universal de dez capacidades, que deverá ser sempre adaptada às especificidades culturais do contexto em estudo.

A teoria das capacidades foi considerada mais recentemente um framework inovador para estudar também a população de pessoas com uma problemática de saúde mental, uma vez que oferece critérios concretos para promover o recovery e a cidadania. O referencial das capacidades apresenta coerências teóricas e aplicativas com a Psicologia Comunitária: a integração das duas disciplinas pode fomentar uma mudança transformativa no sistema de saúde mental.

O objectivo do presente estudo é o desenvolvimento de um questionário inspirado nesta abordagem teórica e construído em colaboração com utilizadores de serviços comunitários de saúde mental. O processo colaborativo de construção do instrumento, chamado Questionários das Capacidades para a Saúde Mental Comunitária (QC-SMC), permitiu realçar a perspectiva dos utilizadores, promovendo tanto o empowerment dos/as participantes bem como a adaptação cultural das capacidades à saúde mental.

Apresentam-se também os primeiros estudos de validação da medida, nomeadamente a validade facial e de conteúdo.

**Palavras-chave:** psicologia comunitária; abordagem das capacidades; adaptação cultural; questionário



### Abstract

The capabilities approach emerges as an alternative indicator in the field of economy and development and was adopted in studies on the quality of life of vulnerable populations. Capabilities are essentially freedom of choice and agency: its promotion is also determined by the political, social and institutional context. The author Martha Nussbaum has drawn up a list of ten universal capabilities that should always be adapted to each study context and culture.

The capabilities theory was considered more recently an innovative framework to study the population of people with mental health challenges, as it offers concrete criteria to promote recovery and citizenship. The capabilities framework presents theoretical and applicative coherences with Community Psychology: the integration of these two disciplines may foster a transformative change in the mental health system.

The aim of the current study is to develop a questionnaire inspired in this theoretical approach and constructed with the collaboration of users of community mental health services. The collaborative process to develop the instrument, named Capabilities Questionnaires for Community Mental Health (CQ-CMH), allowed highlighting user's perspective, promoting participant's empowerment as well as a cultural adaptation of capabilities to the mental health field.

Initial studies to validate the measure are also presented, namely face and content validity.

**Keywords:** community psychology; capabilities approach; cultural adaptation; questionnaire





## Introdução

A abordagem das capacidades foi introduzida pela primeira vez pelo economista indiano Amartya Sen (1993; 1999), que esteve envolvido na elaboração do Relatório de Desenvolvimento Humano do Programa de Desenvolvimento das Nações Unidas. Neste contexto, a abordagem das capacidades tem sido proposta como referencial teórico para avaliar e comparar a qualidade de vida dos indivíduos.

A capacidade é definida como a oportunidade individual de ponderar entre várias alternativas alcançáveis e de realizar aquelas que se consideram relevantes (Alkire, 2002; Robeyns, 2005). Neste sentido, é central o exercício de liberdade e a autodeterminação (*agency*) da pessoa. Ao mesmo tempo, a liberdade individual é influenciada pelas oportunidades do contexto de vida da pessoa, apontando assim para a existência de uma responsabilidade social e institucional.

Esta perspectiva teórica foi integrada e aplicada pela filósofa Martha Nussbaum em estudos sobre mulheres em países em desenvolvimento, cujas oportunidades de vida são reduzidas (Nussbaum, 2000). Após anos de estudos transculturais, Nussbaum elaborou uma lista de capacidades de carácter universal e fundamental com o intuito de ser aplicada em estudos sobre a qualidade de vida e na definição de políticas públicas. A lista é composta pelas seguintes capacidades (ver Nussbaum, 2000, pp. 78-80): 1) VIDA, i.e. a esperança de viver bem até a velhice, sem morrer prematuramente; 2) SAÚDE FÍSICA, i.e. ter boas condições de saúde; 3) INTEGRIDADE FÍSICA, que consiste na liberdade de estar em segurança no meio ambiente; 4) SENSAÇÕES, IMAGINAÇÃO E PESAMENTO, que reflecte a capacidade de raciocinar e pensar criativamente; 5) EMOÇÕES, i.e. a capacidade de viver as emoções; 6) RAZÃO PRÁTICA, i.e. a capacidade de reflexão crítica e de planeamento da própria vida; 7) AFILIAÇÃO, que representa a capacidade de interagir e viver com as outras pessoas; 8) OUTRAS ESPÉCIES, que reflecte a capacidade de relacionar-se com os animais e a natureza; 9) JOGAR/DIVERTIR-SE, ou por outras palavras, aproveitar das actividades recreativas; 10) CONTROLO SOBRE O PRÓPRIO AMBIENTE, que questiona sobre a liberdade de expressão, de fazer escolhas políticas, de ter oportunidades de emprego.

Segundo a autora, todas as pessoas deviam ser capazes – ter a oportunidade – de desenvolver um nível mínimo de cada capacidades, no sentido de alcançarem uma vida digna de ser vivida. No entanto, a lista de capacidades proposta pela autora é interpretada como uma estrutura de princípios básicos e fundamentais que deverá ser readaptada e ajustada ao contexto e à cultura em análise (Nussbaum, 2011).

A abordagem das capacidades apresenta coerências teóricas com os valores e modelos da Psicologia Comunitária, quais o empowerment, o recovery e a integração comunitária. À semelhança do modelo de empowerment, a teoria das capacidades prioriza a autodeterminação e o poder de controlo das pessoas, fomentando uma análise contextual com enfoque nas oportunidades e liberdades proporcionadas pelo ambiente social, político e institucional (Shinn, 2014). A teoria das capacidades, como o modelo de *recovery*, põe no centro da atenção as pessoas, as suas experiências e acções, sublinhando a importância da liberdade e escolha entre actividades e papéis socialmente reconhecidos (Hopper, 2007).

A abordagem das capacidades pode ser utilizada como um novo princípio orientador e transformativo na área de saúde mental, com dimensões específicas que focalizam reais oportunidades de inserção social para desencadear o processo de recovery (O'Connell,



Davidson, 2010) e que permitem ajudar a identificar os elementos mais/menos eficazes nos contextos de suporte (Shinn, 2015; Davidson, Ridgway, Wieland & O'Connell, 2009).

O presente estudo tem por objectivo desenvolver uma medida de capacidades que responda a este desafio, através de um processo colaborativo com utilizadores de serviços comunitários de saúde mental. A escolha de métodos colaborativos considera-se fundamental, uma vez que a maioria das medidas na área de saúde mental foi construída só por profissionais sem ter em consideração a perspectiva das pessoas com experiência pessoal em doença mental (Rose et al., 2011).

### Método

O objectivo do estudo é desenvolver um instrumento para investigar em que medida os serviços de saúde mental promovem as capacidades individuais das pessoas com problemáticas de saúde mental. Foram adoptados métodos de investigação colaborativa, com o intuito de promover o empowerment dos/as participantes, bem como a aquisição de novos conhecimentos úteis e sustentáveis para a comunidade em estudo (Trickett & Espino, 2004).

#### 1ª Fase: Recolha dos Dados

Para a recolha dos dados foram realizados onze grupos de discussão focalizada com 50 utilizadores voluntários da Associação para o Estudo e Integração Psicossocial (N=36) e da Associação para a Reabilitação e Integração Social Recomeço (N=14) em Lisboa. Do total de participantes, 30% eram mulheres e 70% homens, entre 20 e 58 anos (média = 42; *SD* = 8.79), o 14% estava a estudar, o 28% a trabalhar e o restante 58% participava em outras actividades promovidas pelas associações (por ex. actividade desportiva; formação profissional). Os focus group eram compostos em média por cinco utilizadores e um facilitador (membro da equipa de investigação) com o objectivo de promover a discussão em torno das seguintes perguntas-chave: "Quais são os seus ganhos individuais alcançados através do suporte recebido pelo serviço que frequenta? Nomeadamente nas áreas do emprego; da educação; da habitação; das relações pessoais, sociais e comunitárias; da saúde física e mental". Entre os participantes de cada grupo era também eleito um/a porta-voz com a função de anotar as respostas do grupo.

#### 2ª Fase: Análise dos Dados

As anotações dos grupos foram transcritas em formato digital e serviram como base para uma análise qualitativa dos dados. No sentido de prosseguir nos métodos colaborativos, foi constituído um painel de investigação (*steering committee*) composto por dois membros da equipa de investigação e três utilizadores voluntários, líderes da *Rede Nacional das Pessoas com Experiência de Doença Mental*.

De acordo com a estratégia de consenso para interpretação dos dados (Barker and Pistrang, 2005), foram discutidos os dados e agrupados em dimensões e sub-dimensões criadas pelo painel. Os conteúdos mais frequentes de cada sub-dimensão foram seleccionados para compor os itens do questionário (i.e. 104 itens de um total de 700 conteúdos transcritos). Esta etapa resultou em 20 encontros em que utilizadores e investigadores colaboraram estritamente, trocando conhecimentos e demonstrando confiança recíproca.



### **3ª Fase: Construção do Questionário**

A terceira etapa foi desenvolvida pelo mesmo *steering committee* em mais doze encontros, com o objectivo de construir o questionário inspirado-se no referencial teórico da Nussbaum (2000). A lista da autora serviu para estruturar o instrumento e organizar os itens pelas capacidades. O *steering committee* analisou em profundidade as definições de cada capacidade e procurou a coerência destas com os itens seleccionados na fase anterior. Neste sentido, as respostas dos focus group representam indicadores de capacidades. A medida que se discutia o ajustamento dos dados recolhidos, elaborava-se uma definição das capacidades específica do contexto em estudo. De facto, foram acrescentados conteúdos identificados nas respostas dos utilizadores às definições originais da Nussbaum, que reflectem dimensões do processo de empowerment, recovery e integração comunitária das pessoas com problemáticas de saúde mental.

### **4ª Fase: Validade Facial e de Conteúdo**

A versão obtida de 104 itens, ordenados pelas 10 capacidades, foi aplicada a um novo grupo de 15 utilizadores voluntários da organização AEIPS (20% mulheres, média de idade 40 anos) com o objectivo de aferir a facilidade de compreensão e relevância. Todos/as participantes consideraram os temas abordados no instrumento muito relevantes, mas o preenchimento do mesmo foi julgado demasiado longo e cansativo.

Neste sentido, constituiu-se um novo painel de investigação para uma avaliação em profundidade da validade de conteúdo, com o intuito de reduzir a medida. Foram convidadas diversas fontes de *expertise* para esta etapa de validação do questionário, nomeadamente mais três utilizadores com uma longa experiência de utilização de serviços de saúde mental, auto-representação e actividades de ajuda mútua; dois *senior researchers* em Psicologia Comunitária (um perito em validação de medidas e um na abordagem das capacidades); três técnicos de programas comunitários em saúde mental. Os membros do painel, composto por um total de 8 pessoas com uma média de 15, 5 anos de experiência como utilizador/investigador/profissional, avaliaram individualmente cada item do questionário em termos quantitativos com uma escala Likert de 5 pontos acerca da relevância, e em termos de observações qualitativas acerca da clareza e adequação dos itens (Delgado-Rico, Carretero-Dios & Ruch, 2012).

A equipa de investigação apresentou os resultados qualitativos e quantitativos aos membros do painel em dois encontros, com o objectivo de se discutir e produzir uma versão definitiva.

## **Resultados**

### **O Processo Empowering**

O painel de investigação da segunda e terceira etapa deste estudo, foi constituído para assegurar os processos colaborativos do estudo na elaboração dos conteúdos do questionário. De facto, os modelos de investigação participativa/colaborativa sugerem a criação de uma equipa mista, em que os membros da comunidade em estudo sejam maioritárias comparando com os profissionais (Nelson & Prilleltensky, 2005).

O trabalho do *steering committee* permitiu uma efectiva partilha de poder e controlo, uma troca de conhecimentos e uma valorização da perspectiva dos utilizadores. O ambiente de confiança entre os membros da comunidade e os profissionais desencadeou uma relação de



suporte: a comunicação era aberta e o trabalho foi adaptado segundo as necessidades e a linguagem dos membros do grupo.

### **O Questionário das Capacidades**

O Questionário das Capacidades para a Saúde Mental Comunitária (QC-SMC) apresentou bons índices de validade de conteúdo (4ª etapa do estudo), nomeadamente um *content validity index* de 0,89 (Delgado-Rico, Carretero-Dios & Ruch, 2012). Considerando ambos os resultados quantitativos e qualitativos, foram tomadas várias decisões nos encontros finais do painel, nomeadamente: 29 itens foram modificados em termos de formulação/linguagem utilizada, 2 itens foram acrescentados e 8 removidos por causa da redundância de conteúdos.

A versão definitiva do questionário apresenta assim 98 itens distribuídos pelas 10 capacidades, com uma escala Likert de 4 pontos (entre o 'Consegui alcançar totalmente' e 'Não consegui alcançar de todo') e uma opção de 'não se aplica'.

Pretende-se analisar esta versão em termos psicométricos e de validade com o objectivo de continuar a reduzir e afinar.

### **A Adaptação Ecológica das Capacidades**

O trabalho de ajustamento entre os dados recolhidos através dos focus group e a lista da Nussbaum (3ª etapa do estudo), resultou numa adaptação cultural das capacidades à área da saúde mental. Às capacidades foram acrescentados elementos específicos identificados nas respostas dos utilizadores, que reflectem as dimensões de empowerment, recovery e integração comunitária. A primeira capacidade foi denominada "Vida e Saúde" (composta por 17 itens) e recolhe questões de saúde tanto física como mental: cuidar da própria condição física, fazer os exames médicos necessários e ter controlo sobre os processos de cuidados; gerir a medicação e os processos de cuidados psiquiátricos; estar activo/a no processo de recovery e reduzir os internamentos; ter uma alimentação equilibrada e hábitos saudáveis.

A segunda capacidade, "Integridade Física" (composta por 6 itens), consiste na liberdade de deslocar-se livremente na comunidade, utilizar e aproveitar dos espaços e recursos públicos; sentir-se seguro e protegido na própria habitação; não ter receio de ser vítima de abuso sexual ou de violência.

"Sentidos, Imaginação e Pensamento" (terceira dimensão com 9 itens), é a capacidade que envolve a utilização de sentidos, imaginação, pensamento e razão de forma construtiva e produtiva para a própria vida; ter e/ou procurar ter uma boa escolaridade bem como um nível intelectual que reflecta os próprios interesses; ser informado/a, culto/a, interessado/a, criativo/a.

A quarta capacidade denominada "Emoções, Sentimentos e Relações Afectivas" (composta por 15 itens), consiste em ser capaz de instaurar e viver relações saudáveis, em que haja respeito recíproco; ter sentimentos de empatia e responsabilidade; amar-se a si próprio/a; ter autoconfiança e optimismo em relação ao futuro.

"Razão Prática e Reflexão Crítica" é a sexta dimensão (composta por 11 itens) que investiga sobre a capacidade de analisar e reflectir criticamente sobre as situações e o próprio ambiente de vida; ser capaz de tomar decisões, de procurar soluções; ser capaz de gerir compromissos.

A sexta capacidade "Afiliação, Interações Sociais e Comunitárias" (com 14 itens) consiste no



respeito e na consideração por si próprio/a e pelos/as outros/as; na não discriminação e estigmatização; nas oportunidades de desenvolver relações sociais, comunitárias e familiares; no desenvolvimento do sentimento de pertença à comunidade; nas oportunidades de ajuda interpares.

“Outras Espécies” é a oitava dimensão que descreve a capacidade de conviver bem com a natureza, com os animais e de aproveitar dos espaços livres públicos, enquanto “Lazer” é a nona capacidade sobre a oportunidade de se divertir e aproveitar das actividades recreativas (ambas compostas por 3 itens).

A última capacidade “Controlo do próprio Ambiente” é a mais extensa dimensão (com 20 itens), em que foram acrescentados, para além dos temas originais da Nussbaum (2000), elementos de participação cívica; de controlo dos próprios recursos; de organização e controlo da própria rotina, bem como da própria situação financeira; da independência familiar e habitacional; da autonomia dos serviços de saúde mental.

## Conclusão

### Limites do Estudo

A opção metodológica do presente estudo tem como carácter inovador a participação activa de membros de uma população que historicamente teve um papel passivo no sistema de saúde mental, em particular na implementação e avaliação dos serviços de suporte. O processo colaborativo também permitiu produzir uma medida contextualmente valida e específica, o que pode, por outro lado, dificultar a sua generalizabilidade e aplicação a outros contextos. Assim, recomenda-se que, em estudos futuros com outros grupos, se procure desenvolver em primeiro lugar uma etapa de validação da validade de conteúdo através de métodos colaborativos, para aferir a relevância e pertinência dos conteúdos e da linguagem utilizada na medida com membros da comunidade em estudo.

A versão definitiva do questionário aqui apresentado é um instrumento ainda bastante extenso, composto por 98 itens, o que pode inviabilizar o seu preenchimento. Neste sentido, estudos em curso estão a analisar as qualidades psicométricas do questionário com o objectivo de produzir uma versão reduzida e rigorosa, averiguando a sua validade, confiabilidade e consistência interna.

Por fim, a população em estudo pode apresentar alguns problemas de literacia que poderão comprometer a compreensão do questionário (Lincoln et al., 2017). Por conseguinte, os/as participantes à recolha de dados quantitativos deverão ser acompanhados/as por pessoas formadas e especializadas, para garantir o rigor dos dados recolhidos.

### Notas conclusivas

A colaboração com os/as utilizadores permitiu obter resultados validos do ponto de vista ecológico, ou seja, validados pelos representantes da população em estudo (Christens & Perkins, 2008). Isso permitiu uma correcta interpretação dos dados e a produção de um questionário relevante para a própria comunidade em estudo.

O processo de adaptação cultural das capacidades de Nussbaum, permitiu elaborar indicadores de capacidades específicos e contextuais, contribuindo assim para a integração da teoria das capacidades na saúde mental e para a definição de um modelo inovador e transformativo.



De forma a apurar a validade do questionário do ponto de vista psicométrico, foram desenhadas novas etapas de validação: actualmente está a ser explorada a estrutura factorial da medida.

O Questionário das Capacidades tem por missão servir para os/as utilizadores como exercício de reflexão critica acerca dos percursos individuais e dos ganhos alcançados através do suporte recebido; para os serviços de saúde mental para orientar a intervenção no sentido de promover a integração e a autodeterminação dos/as utilizadores.

### Agradecimentos

Agradecemos a participação de todos/as os/as utilizadores/as que permitiram o desenvolvimento do instrumento com a missão de promover as capacidades das pessoas com uma problemática de saúde mental.

Este trabalho foi desenvolvido com um financiamento da Fundação para a Ciência e Tecnologia (SFRH/BD/92224/2013), que muito se agradece pela concessão do apoio.

### Contacto para correspondência

Beatrice Sacchetto – Doutoranda em Psicologia Comunitária  
ISPA-Instituto Universitário  
Rua Jardim do Tabaco nº34, 1149-041, Lisboa (PT)  
[bsacchetto@ispa.pt](mailto:bsacchetto@ispa.pt)

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**Annex II – ISPA-Instituto Universitário Ethical Committee Approval**





Comissão de Ética de Investigação  
ISPA - Instituto Universitário de Ciências  
Psicológicas, Sociais e da Vida  
Rua Jardim do Tabaco, 34,  
1149-041 Lisboa  
Telefone: (351) 218 811 700  
Fax: (351) 218 860 954

## COMISSÃO DE ÉTICA

### PARECER

**Título do projeto:** Validation and transcultural adaptation of the Capability Questionnaire (CQ) for users of community mental health services

**Investigador responsável:** Beatrice Sacchetto

**Instituição/Curso:** ISPA- Instituto Universitário

**Telefone para contato:** [bsacchetto@ispa.pt](mailto:bsacchetto@ispa.pt)

O protocolo do estudo apresenta objetivos relevantes. Foram descritos adequadamente os métodos e procedimentos a adotar e estes respeitam os direitos humanos e as recomendações constantes nos documentos nacionais e internacionais relativos à ética em investigação.

Assim, o parecer da Comissão de Ética do ISPA-Instituto Universitário é favorável à realização do estudo em epígrafe.

Qualquer alteração futura aos procedimentos descritos do estudo que possam colidir com os critérios éticos de investigação com seres humanos ou animais não humanos constantes nos referidos regulamentos, exigem uma reapresentação do pedido de apreciação a esta Comissão.

Recomendação: Atendendo aos subscritores do documento recomendamos que o o único logotipo em cabeçalho deve ser o do ISPA.

**Comissão Ética do ISPA – Instituto Universitário**

(Assinatura do Presidente da CE)

Lisboa, 22 de Abril de 2016.



**Annex III – Invitation Letters to Community Mental Health Programs**



Exmo/a Senhor/a

Dr/a

Presidente da

XXX

Lisboa,

**Assunto:** Participação no estudo “Validação do *Questionário das Capacidades para o contexto de Saúde Mental Comunitária (QC-SMC)* para os utilizadores dos serviços comunitários de saúde mental”

O estudo referido em epígrafe é um projecto de Doutoramento apoiado pela Fundação para a Ciência e Tecnologia (SFRH/BD/92224/2013) e desenvolvido no ISPA – Instituto Universitário, sob orientação científica do Professor Doutor José Ornelas (ISPA-IU) e da Professora Doutora Manuela Calheiros (ISCTE-IUL).

A área de Psicologia Comunitária, coordenada pelo Professor Doutor José Ornelas do ISPA-IU, tem uma longa tradição de investigação na área da saúde mental comunitária, com o objectivo de criar linhas orientadoras para a melhoria dos serviços no sentido de proporcionarem o recovery e a integração comunitária aos seus utilizadores.

O presente projecto pretende validar um questionário que foi previamente construído em colaboração com um grupo de utilizadores de serviços de saúde mental em Lisboa. O questionário pretende medir as capacidades dos utilizadores e pode contribuir para a avaliação de serviços de saúde mental de base comunitária.

Neste sentido convidamos a V. organização e os utilizadores que nela participam, a juntar-se ao estudo.

SFRH/BD/92224/2013

O protocolo de entrevista será aplicado pela Dra. Beatrice Sacchetto, e outros colaboradores com formação para o efeito. Os contactos para operacionalizar esta colaboração podem ser estabelecidos através do email [bsacchetto@ispa.pt](mailto:bsacchetto@ispa.pt) ou para o tel. 969223253.

Em anexo enviamos o consentimento informado a ser apresentado aos participantes de modo a garantir o seu anonimato e a informar sobre o propósito, interesse e procedimento do estudo.

Ao dispor para quaisquer esclarecimentos complementares.

Os nossos melhores cumprimentos

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José Ornelas  
(Orientador Científico)

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Beatrice Sacchetto  
(Doutoranda em Psicologia Comunitária)



Exmo/a Senhor/a

Dr/a

Presidente da

XXX

Lisboa,

**Assunto:** Nova participação no estudo “*Validação do Questionário das Capacidades alcançadas em contexto de Saúde Mental Comunitária (QCA-SMC) para os utilizadores dos serviços comunitários de saúde mental*”

No decurso do biénio 2015-2016 a V. organização participou no estudo citado em epígrafe com o objectivo de validar um questionário previamente construído em colaboração com utilizadores de serviços comunitários de saúde mental.

Neste sentido, agradecemos muito a V. colaboração e informamos que foi concluída com sucesso a primeira etapa exploratória do estudo, na qual participaram ao todo 332 utilizadores de diversas organizações comunitárias do território português. Conseguimos alcançar os resultados desejados, ou seja, uma versão do questionário mais breve e rigorosa. Nomeadamente, o Questionário das Capacidades passou a ser composto por 48 itens comparando com a versão inicial de 98 itens.

A nossa investigação prevê uma segunda e última fase confirmatória do estudo, com o objectivo de confirmar a estrutura da medida para ser divulgada e utilizada como um instrumento para medir as capacidades alcançadas pelos utilizadores de serviços comunitários de saúde mental.

Neste sentido, vimos pedir novamente a vossa participação à uma nova fase de recolha dos dados, em que os critérios de inclusão se mantem idênticos a fase anterior, i.e. podem participar utentes (que não participaram na primeira recolha) maiores de 18 anos; com uma problemática de saúde mental; com pelo menos 2 meses de participação na organização.

Vimos assim convidar a V. organização e os utilizadores que nela participam, a juntar-se nesta etapa, que irá realizar-se entre Janeiro e Maio de 2018.

O protocolo de entrevista será aplicado novamente pela Dra. Beatrice Sacchetto, ou outros/as colaboradores/as com formação para o efeito. Os contactos para operacionalizar esta colaboração podem ser estabelecidos através do email [bsacchetto@ispa.pt](mailto:bsacchetto@ispa.pt) ou para o tel. 969223253.

Em anexo enviamos também o consentimento informado a ser apresentado aos participantes de modo a garantir o seu anonimato e a informar sobre o propósito, interesse e procedimento do estudo.

Ao dispor para quaisquer esclarecimentos complementares.

Os nossos melhores cumprimentos

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José Ornelas  
(Orientador Científico)

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Beatrice Sacchetto  
(Doutoranda em Psicologia Comunitária)

Exmos/as Senhores/as  
Direcção da

Lisboa,

**Assunto:** Participação no estudo “Validação do *Questionário das Capacidades alcançadas em Saúde Mental Comunitária (QCA-SMC)* para os utilizadores dos serviços comunitários de saúde mental”

O estudo referido em epígrafe é um projecto de Doutoramento apoiado pela Fundação para a Ciência e Tecnologia (SFRH/BD/92224/2013) e desenvolvido no ISPA – Instituto Universitário, sob orientação científica do Professor Doutor José Ornelas (ISPA-IU) e da Professora Doutora Manuela Calheiros (CICPSI-UL).

A área de Psicologia Comunitária, coordenada pelo Professor Doutor José Ornelas do ISPA-IU, tem uma longa tradição de investigação na área da saúde mental comunitária, com o objectivo de criar linhas orientadoras para a melhoria dos serviços no sentido de proporcionarem o recovery e a integração comunitária aos seus utilizadores.

O presente projecto pretende validar um questionário (*Questionário das Capacidades alcançadas em Saúde Mental Comunitária - QCA-SMC*) que foi previamente construído em colaboração com um grupo de utilizadores de serviços de saúde mental em Lisboa e que já foi aplicado a 332 utilizadores de diversas organizações comunitárias do território português. A investigação prevê uma última fase de recolha dos dados, com o objectivo de confirmar a estrutura do questionário para ser divulgado e utilizado como um instrumento para medir as capacidades alcançadas pelos utilizadores de serviços comunitários de saúde mental.

SFRH/BD/92224/2013

Neste sentido convidamos a V. organização e os utilizadores que nela participam, a juntar-se nesta etapa do estudo, que irá realizar-se entre Janeiro e Maio de 2018. Os critérios de participação são serem pessoas maiores de 18 anos; com uma problemática de saúde mental; com pelo menos 2 meses de participação na V. organização.

O protocolo de entrevista será aplicado pela Dra. Beatrice Sacchetto, e outros/as colaboradores/as com formação para o efeito. Os contactos para operacionalizar esta colaboração podem ser estabelecidos através do email [bsacchetto@ispa.pt](mailto:bsacchetto@ispa.pt) ou para o tel. 969223253.

Mais informamos que, conforme os princípios éticos de investigação adoptados, será enviado um relatório descritivo dos procedimentos e resultados do estudo após a sua conclusão para todas as organizações participantes.

Em anexo enviamos o consentimento informado que será apresentado durante a recolha pela equipa de investigação aos participantes de modo a garantir o seu anonimato e a informar sobre o propósito, interesse e procedimento do estudo.

Ao dispor para quaisquer esclarecimentos complementares.

Os nossos melhores cumprimentos

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José Ornelas  
(Orientador Científico)

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Beatrice Sacchetto  
(Doutoranda em Psicologia Comunitária)

**Annex IV – Consent Forms**



**ISPA-Instituto Universitário (ISPA-IU)**  
**Documento de Consentimento Informado para fins de Investigação**

Organizações Participantes: Associação para o Estudo e Integração Psicossocial (AEIPS) (Lisboa, Portugal); Recomeço, Hospital Dr. Fernando da Fonseca EPE (Lisboa, Portugal)

Este documento de consentimento informado aplica-se a adultos com idade igual ou superior a 18 anos.

Nome do/a participante: \_\_\_\_\_ Idade: \_\_\_\_\_

Este documento informa-o(a) acerca do estudo sobre “As capacidades promovidas pelos serviços de saúde mental” e da sua participação na mesma. Por favor, leia cuidadosamente a informação apresentada e não hesite em questionar sobre o que pretender ver esclarecido. A participação neste estudo de investigação é inteiramente voluntária, pelo que, uma vez participante poderá a qualquer momento anular a sua colaboração. Não terá quaisquer penalizações caso recuse participar. No final ser-lhe-á entregue uma cópia deste documento.

**1. Objectivo do Estudo:**

Este estudo tem como objectivo primordial contribuir para uma melhor compreensão sobre a forma como a rede de serviços de saúde mental, podem melhorar a resposta que é dada às necessidades de integração comunitária de pessoas com experiência de doença mental, nomeadamente nos seus objectivos de habitação, emprego, educação, familiares e sociais, entre outros. Pretende-se igualmente publicar os resultados desta investigação para que outras organizações similares os possam utilizar, tanto no desenho de melhores programas e serviços como no aperfeiçoamento dos que já existem.

**2. Procedimentos e tempo aproximado de duração do Grupo de Discussão Focalizada**

A participação neste estudo envolve a realização de uma reunião de debate em grupo com a duração aproximada de duas horas que pretende essencialmente conhecer qual a influência dos serviços de saúde mental na prossecução e alcance dos seus objectivos enquanto seus utilizadores. A facilitação do grupo de discussão focalizada estará a cargo de dois membros da equipa de investigação do ISPA-Instituto Universitário, com o apoio dos profissionais da rede de serviços.

**3. Descrição dos inconvenientes e/ou riscos que podem resultar da participação neste estudo**

É possível que da sua participação possa surgir algum desconforto em falar sobre a sua experiência e de como é que os programas o(a) ajudaram ou têm ajudado a conquistar os seus objectivos. Contudo é pouco provável que se sinta em risco. Se, por acaso, no final da entrevista, se sentir incomodado(a) ou quiser emitir uma opinião acerca das perguntas formuladas ou da metodologia utilizada ou algum ou aspecto relacionado com o trabalho em grupo, pode referi-lo aos facilitadores ou contactar o investigador principal do estudo.

#### **4. Benefícios em participar**

Os potenciais benefícios para o campo científico deste estudo que podem resultar deste grupo de discussão são o aumento do conhecimento sobre o impacto dos serviços de saúde mental e dos seus programas na vida daqueles(as) que os utilizam. Não existem benefícios directos associados à participação neste estudo; contudo, o mesmo pode conduzir a melhorias significativas nos programas em que participa actualmente ou eventualmente venha a participar.

#### **5. Informação para contacto**

Se tiver quaisquer questões sobre esta investigação, por favor contacte José Ornelas ou Beatrice Sacchetto através do número de telefone 21 881 17 00 ou [jornelas@ispa.pt](mailto:jornelas@ispa.pt), ou ainda [bsacchetto@ispa.pt](mailto:bsacchetto@ispa.pt). Para informações adicionais sobre o consentimento informado ou os seus direitos enquanto participante, por favor, não hesite em contactar.

#### **6. Confidencialidade**

Será mantida confidencialidade em toda a informação pessoal que fornecer ao longo da entrevista: a informação individualizada partilhada será restringida à equipa que esta envolvida nesta investigação e aos membros dos grupos de discussão focalizada. Como participante tem o direito de, a qualquer momento, pedir ao facilitador que não revele os seus comentários ou afirmações. Para preservar a confidencialidade da informação de outros(as) participantes do estudo, é pedido a todos que não reproduzam os comentários ou respostas que outros(as) participantes tenham dado no contexto dos grupos de trabalho.

#### **Declaração de participação**

**Declaro que li a informação contida neste documento e que a mesma me foi transmitida verbalmente. Todas as questões acerca desta investigação vi respondidas e é livre e voluntariamente que eu decido participar.**

\_\_\_\_\_

Data

\_\_\_\_\_

Assinatura do(a) entrevistador(a)

Consentimento obtido por:

\_\_\_\_\_

Data

\_\_\_\_\_

Assinatura

\_\_\_\_\_

Facilitador/a do Grupo



# Consentimento Informado

## Convite

Estamos a convidá-lo/a a participar num estudo dirigido pela Dra. Beatrice Sacchetto, sob orientação científica do Professor Doutor José Ornelas (Área de Psicologia Comunitária, ISPA-IU) e da Professora Doutora Manuela Calheiros (CIS, ISCTE - IUL; CICPSI - UL).

É importante que compreenda o objectivo, os procedimentos e o interesse deste estudo.

Leia com atenção esta folha de informação e se desejar, informe-se junto das pessoas da sua confiança ou junto da equipa de investigação para esclarecer as dúvidas que possa ter.

## Qual é o propósito do estudo?

Com este estudo, pretendemos validar o Questionário de Capacidades no contexto da Saúde Mental Comunitária (QC-SMC), construído previamente por um painel de investigadores e utilizadores de serviços comunitários de saúde mental.

O questionário pretende medir as capacidades dos utilizadores, interpretadas como domínios para avaliar a qualidade de vida (Nussbaum, 2000).

## Qual é o interesse em participar?

Foi convidado/a a participar porque gostaríamos de saber a sua experiência enquanto utilizador/a de organizações de saúde mental na comunidade. Nomeadamente, as capacidades que tem alcançado desde que frequenta os seus serviços.

Isso ajuda-nos a compreender de que forma essas organizações podem ter influência na qualidade de vida das pessoas com problemáticas de saúde mental. Os resultados desta investigação têm como objectivo último contribuir para a melhoria dos serviços prestados, da qual poderá retirar um benefício indirecto.

## Como é que vou participar?

A participação consiste no preenchimento de 4 questionários e uma ficha de caracterização individual. O preenchimento deverá durar entre 40 minutos e uma hora e será acompanhado por um membro da equipa de investigação para auxiliar no que for necessário.

Se concordar em participar deverá fornecer o seu consentimento por escrito na folha a seguir (Consentimento de Participação).

A sua participação neste estudo é inteiramente voluntária. Cabe a si aceitar participar e é livre para abandonar o estudo em qualquer altura. Isso não irá afectar o suporte ou tratamento que recebe.

Contudo, é natural que possa surgir algum desconforto ao falar sobre a sua experiência. Se quiser emitir uma opinião acerca das perguntas formuladas ou da metodologia utilizada, pode contactar para: Dr.ª Beatrice Sacchetto – bsacchetto@ispa.pt.

## A minha participação será confidencial?

A sua experiência fará parte da informação recolhida neste estudo e será apresentada de forma global sem identificar os participantes, pelo que se garante a confidencialidade da informação dada. O Consentimento de Participação com a sua assinatura será arquivado em separado dos restantes questionários, os quais receberão um código de identificação. Assim, o seu nome nunca aparecerá em quaisquer relatórios do estudo, comunicações ou publicações.

**Exemplar para o/a participante**

## Consentimento de participação

Projecto: **Validação e adaptação transcultural do Questionário das Capacidades para os utilizadores dos serviços comunitários de saúde mental** (SFRH/BD/92224/2013)

Nome do/a participante \_\_\_\_\_ Idade \_\_\_\_\_

Concordo em participar neste estudo e confirmo que li e compreendi a folha de informação para o estudo supracitado e que tive a oportunidade de colocar questões. Compreendo que a minha participação é voluntária e que sou livre de desistir em qualquer altura, sem explicações, e sem que o tratamento, suporte que recebo ou direitos legais sejam afectados. Foi-me totalmente explicado o propósito do estudo, forma de participação e dos procedimentos envolvidos.

Assinatura do/a participante \_\_\_\_\_ Data \_\_\_\_/\_\_\_\_/\_\_\_\_

Assinatura do/a investigador/a \_\_\_\_\_ Data \_\_\_\_/\_\_\_\_/\_\_\_\_

**Exemplar para o projecto**

## Consentimento de participação

Projecto: **Validação e adaptação transcultural do Questionário das Capacidades para os utilizadores dos serviços comunitários de saúde mental** (SFRH/BD/92224/2013)

Nome do/a participante \_\_\_\_\_ Idade \_\_\_\_\_

Concordo em participar neste estudo e confirmo que li e compreendi a folha de informação para o estudo supracitado e que tive a oportunidade de colocar questões. Compreendo que a minha participação é voluntária e que sou livre de desistir em qualquer altura, sem explicações, e sem que o tratamento, suporte que recebo ou direitos legais sejam afectados. Foi-me totalmente explicado o propósito do estudo, forma de participação e dos procedimentos envolvidos.

Assinatura do/a participante \_\_\_\_\_ Data \_\_\_\_/\_\_\_\_/\_\_\_\_

Assinatura do/a investigador/a \_\_\_\_\_ Data \_\_\_\_/\_\_\_\_/\_\_\_\_



**Annex V – Invitation Letter for the Assessment of the Content Validity**





## **Convite à participação no painel de avaliação da VALIDADE DE CONTEÚDO**

Estamos a convidá-lo(a) a participar numa fase de um projecto de Doutoramento, intitulado “*Validation and transcultural adaptation of the Capability Questionnaire for users of community mental health services*”, financiado pela Fundação para a Ciência e Tecnologia (SFRH/BD/92224/2013), sob orientação científica do Professor Doutor José Ornelas e da Professora Doutora Manuela Calheiros e sob acolhimento da Unidade de Investigação em Psicologia (UIPES, ISPA-IU) e do Centro de Investigação e de Intervenção Social (CIS, IUL). Neste sentido, a convidamos a participar na avaliação da validade de conteúdo do *Questionário de Capacidades no contexto da Saúde Mental Comunitária (QC-SMC)*, construído previamente por um painel de investigadores e utilizadores de serviços de saúde mental na comunidade.

O questionário pretende medir as capacidades dos utilizadores alcançadas através do suporte dos serviços de saúde mental na comunidade, no sentido do referencial teórico da abordagem das capacidades da autora Martha Nussbaum (2000, 2003), que indicou domínios fundamentais para avaliar a qualidade de vida. Através de um trabalho qualitativo e colaborativo de levantamento de testemunhos dos utilizadores durante discussões de grupo focalizadas e de revisões analíticas dos dados com base no framework acima mencionado, produziu-se um questionário de 104 itens ordenados por 10 capacidades.

Pretende-se agora avaliar a relevância dos itens por um conjunto de pessoas especialistas em pelo menos um dos temas envolvidos no presente estudo: conhecimento teórico e/ou experiencial dos serviços de saúde mental comunitários; métodos de construção de instrumentos de investigação; abordagem das capacidades da autora Martha Nussbaum (2000).

Neste sentido foram identificadas um total de 9 especialistas, nomeadamente 3 utilizadores, 3 académicos e 3 profissionais dos serviços.

### **Pedimos que para cada item indique:**

- **A relevância numa escala Likert de 5 pontos (de  *muito relevante a nada relevante*);**
- **Eventuais comentários e/ou sugestões de alteração.**

Refere-se ainda que em primeiro lugar a média será efectuada separadamente por cada uma das fontes e que, caso haja forte discordância entre a avaliação dos utilizadores e a avaliação dos académicos ou profissionais, será convocada uma reunião (*web-conference*) para serem discutidas as diferentes perspectivas até se conseguir um consenso.



Se aceitar participar, por favor preencha uma breve ficha de caracterização individual e leia com atenção o resumo do referencial teórico da autora Nussbaum (2000, 2003).

### Ficha de Caracterização Individual

Fonte: Utilizador  Académico  Profissional de serviço

Sexo:

Idade

Habilitações académicas (grau e área): \_\_\_\_\_

\_\_\_\_\_

Área/função específica de trabalho: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Anos de experiência como utilizador/académico/profissional: \_\_\_\_\_

\* Para os utilizadores:

Conhece o seu diagnóstico de saúde mental? Sim  Não

Se sim, poderia por favor indicar qual? (opcional) \_\_\_\_\_

Alguma vez foi internado(a) num hospital para tratamento psiquiátrico? Se sim, quantas vezes? \_\_\_\_\_

Há quanto tempo foi o último internamento? \_\_\_\_\_





## **Breve descrição do referencial teórico da abordagem das capacidades da Martha Nussbaum (2000)**

As variáveis em estudo inspiram-se no enquadramento da abordagem das capacidades. O *capabilities approach* é inovador no sentido que introduz a dimensão da liberdade de escolha da pessoa na avaliação da qualidade de vida (Nussbaum, Sen, 1993). As capacidades são essencialmente avaliadas pelo grau de liberdade de ser e fazer algo que a pessoa valoriza, dependendo tanto das próprias habilidades individuais como das condições proporcionadas pelo contexto institucional e social. Esta perspectiva permite apontar a existência/ausência de oportunidades proporcionadas pelo contexto no sentido de promover as capacidades dos cidadãos.

A abordagem foi introduzida pela primeira vez pelo economista indiano Amartya Sen (1985; 1999), que esteve envolvido na elaboração dos indicadores para avaliar e comparar a qualidade de vida dos indivíduos do Programa de Desenvolvimento Humano das Nações Unidas (United Nations Development Programme, 1990).

Posteriormente, esta abordagem foi desenvolvida pela filósofa Martha Nussbaum (2000, 2003) que, após anos de estudos em vários países acerca da justiça social, identificou uma lista de dez capacidades de importância central para qualquer vida humana, com o objectivo de fornecer uma estrutura para a qualidade de vida, que pode ser adaptada às especificidades de cada contexto e cultura (Nussbaum, 2011).

Promover as capacidades significa portanto promover o acesso a um leque de escolha de atividades e papéis socialmente significativos (Hopper, 2007; O'Connell, Davidson, 2010) e pode ser utilizado como um novo princípio orientador e transformativo na área da saúde mental para identificar as falhas nos contextos de suporte (Davidson et al. 2009; Shinn, In Press).

Na página seguinte encontra a lista de dez capacidades proposta pela autora Nussbaum (2000), que poderá utilizar como material de suporte para avaliar a relevância dos itens do questionário.



## **Lista de capacidades e definições traduzidas para português (Nussbaum, 2000)<sup>1</sup>:**

- 1) VIDA** (*Ser capaz de viver a vida de acordo com a esperança média de vida; não morrer prematuramente [...]*);
- 2) SAÚDE FÍSICA** (*Ser capaz de ter uma boa saúde, incluindo uma saúde reprodutiva, uma alimentação adequada, um abrigo adequado*);
- 3) INTEGRIDADE FÍSICA** (*Ser capaz de deslocar-se livremente [...] por exemplo, sentir-se protegido contra assaltos [...] ter oportunidades de satisfação sexual*);
- 4) SENSações, IMAGINAÇÃO E PESAMENTO** (*Ser capaz de usar os sentidos, de imaginar, pensar e raciocinar, e fazer estas coisas de uma forma verdadeiramente humana, i.e. de forma informada e cultivada por uma adequada educação [...]*)
- 5) EMOÇÕES** (*Ser capaz de ter ligações com as coisas e as pessoas para além de nós mesmos [...] de forma geral, amar, lamentar, experimentar saudade, gratidão e raiva justificada [...]*);
- 6) RAZÃO PRÁTICA** (*Ser capaz de formar uma concepção do bem e de se empenhar em uma reflexão crítica sobre o planeamento da própria vida*);
- 7) AFILIAÇÃO** (a) *Ser capaz de viver com e para com os outros, reconhecer e mostrar preocupação com os outros seres humanos [...]*; b) *Ter as bases sociais do auto-respeito e não-humilhação; podendo ser tratado como um ser digno cujo valor é igual ao dos outros [...]*);
- 8) OUTRAS ESPECIES** (*Ser capaz de conviver com os animais, as plantas e a natureza*);
- 9) BRINCAR** (*Ser capaz de rir, de brincar, de desfrutar de actividades recreativas*);
- 10) CONTROLO SOBRE O PROPRIO AMBIENTE** (a) *Politico- Ser capaz de participar efectivamente em escolhas políticas que governam a própria vida; ter o direito de participação política e a garantia de liberdade de expressão e de associação*; b) *Material- Ser capaz de possuir propriedades [...] ter o direito de procurar emprego da mesma forma que os outros [...]*).

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<sup>1</sup> As definições originais em língua inglesa foram traduzidas para a língua portuguesa por um painel de investigadores e utilizadores numa fase prévia para construção do questionário. O original encontra-se em: Nussbaum, M. (2000). *Human and Women Development: The Capabilities Approach*. New York: Cambridge University Press, 78-80.

## **Annex VI – Key Questions for Focus Group Discussion**



# Projecto de Investigação

## “As capacidades promovidas pelos serviços de saúde mental”

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O propósito desta sessão participativa é identificar os ganhos alcançados graças ao apoio dos serviços e apoios recebidos, nomeadamente nas seguintes áreas:

**EMPREGO; EDUCACAO; HABITACAO; RELACOES SOCIAIS E FAMILIARES; PARTICIPAÇÃO SOCIAL; BEM-ESTAR FÍSICO E MENTAL; OUTROS.**

Por favor, debatam sobre os vossos ganhos e apontam as vossas experiências.

---

1. Quais os ganhos que têm obtido na área do Emprego?

2. Quais os ganhos que têm obtido na área da Educação?

3. Quais ganhos que têm obtido na área da Habitação?

4. Quais os ganhos que têm obtido nas suas Relações Sociais, ex. familiares, de amizade, e/ou íntimas?









**Annex VII – Quantitative Protocol**



# Caracterização individual

## Geral

A. Nome da Organização

B. Código de identificação da Organização

C. Nome do entrevistador/a

D. Data da entrevista

 /  / 

E. Código de identificação do participante

## Dados do entrevistado/a

1. Idade

\_\_\_\_\_ Anos

2. Data de nascimento

\_\_\_\_/\_\_\_\_/\_\_\_\_

3. Sexo

Homem

Mulher

4.1. Nacionalidade

4.2. Etnia

Lusa/Caucasiana

Africana

Brasileira

Países de Leste

Mista

Outra (especifique) \_\_\_\_\_

5. Estado civil

Solteiro/a

Casado/a

União de facto

Parceiro/a

Separado/a

Divorciado/a

Viúvo/a

Outro (especifique) \_\_\_\_\_

6. Tem filhos?

Sim

Não

Se respondeu sim, pode-nos indicar quantos, por favor? \_\_\_\_\_

**Habitação**

7. Qual é a sua situação habitacional?

Vive numa residência comunitária da organização

Vive numa habitação independente.

Especifique, por favor, que tipo de habitação e com quem vive \_\_\_\_\_

Vive com familiares.

Especifique, por favor, com quem \_\_\_\_\_

Outro

Especifique, por favor \_\_\_\_\_

8. Foi uma escolha sua viver nesta solução habitacional?

Sim

Não

9. Desejaria outra solução habitacional?

Sim

Não

Se respondeu sim, especifique qual, por favor \_\_\_\_\_

10. Já se encontrou na situação de sem-abrigo?

Sim

Não

Se respondeu sim:

• Pode-nos indicar quanto tempo esteve nessa situação? \_\_\_\_\_

• Saiu dessa situação através da ajuda da organização?

Sim

Não

**Educação**

11. Qual é o seu grau de qualificação concluído?

Não sabe ler nem escrever

Sabe ler e/ou escrever

Escolaridade básica 1º ciclo (antiga 4ª classe)

Escolaridade básica 2º ciclo (6º ano ou antigo preparatório)

Escolaridade básica 3º ciclo (9º ano ou antigo 5º do secundário)

Escolaridade secundária (10º, 11º e 12º)

Qualificação profissional (ex: um ofício ou uma competência como cabeleireiro/a; trabalho de secretariado; etc.)

Licenciatura

Estudos Pós-Graduados (Mestrado ou Doutoramento)

Outro (por favor especifique)

12. Actualmente é estudante?  Sim  Não

Se respondeu não, pode-nos indicar há quanto tempo foi a sua última experiência na escola \_\_\_\_\_

Se respondeu sim:

• Especifique por favor (que tipo de escola, que tipo de curso, em que área, com outras pessoas da comunidade em geral ou com outras pessoas com problemáticas de saúde mental) \_\_\_\_\_

• Conseguiu esta experiência de estudo através da organização?  Sim  Não

• Foi uma escolha sua realizar esta experiência de estudo?  Sim  Não

13. Desejaria realizar outra experiência de estudo?  Sim  Não

Se respondeu sim, especifique qual, por favor \_\_\_\_\_

### **Formação profissional**

14. Frequenta actualmente um curso de formação profissional?  Sim  Não

Se respondeu sim:

• Especifique por favor (que tipo de curso, em que área, com outras pessoas da comunidade em geral ou com outras pessoas com problemáticas de saúde mental) \_\_\_\_\_

### **Emprego**

15. Qual é a sua situação profissional?

Empregado/a

Voluntário/a

Reformado/a de trabalho

Pensão de invalidez

Estagiário/a

Desempregado/a

Pensão social ou RSI

Outro (especifique) \_\_\_\_\_

16. Se actualmente não está a desenvolver uma actividade profissional:

• Qual e há quanto tempo foi a sua última experiência de emprego? \_\_\_\_\_

17. Se actualmente está a desenvolver uma actividade profissional:

• Especifique, por favor (que tipo de empresa, com qual função, com outras pessoas da comunidade em geral ou com outras pessoas com problemáticas de saúde mental) \_\_\_\_\_

• Conseguiu esta actividade profissional através da organização?  Sim  Não

• Foi uma escolha sua realizar esta actividade profissional?  Sim  Não

18. Desejaria realizar outra actividade profissional?  Sim  Não

Se respondeu sim, especifique qual, por favor \_\_\_\_\_

### **Saúde mental**

19. Conhece o seu diagnóstico de saúde mental?  Sim  Não

Se respondeu sim pode, por favor, indicar-nos qual é? \_\_\_\_\_

20. Que serviços de saúde mental utiliza actualmente? (*assinale as opções que se adequarem*)

Consultas externas (psiquiatria ou psicologia)  Medicamentação psiquiátrica

Unidade de dia no Hospital  Apoio domiciliário

Centro de dia/Fórum sócio-ocupacional  Residência comunitária

Outro. Qual? \_\_\_\_\_

21. Alguma vez foi internado/a num hospital para tratamento psiquiátrico?  Sim  Não

Se respondeu sim, quantas vezes? \_\_\_\_\_

22. Desde que entrou na organização foi internado/a num hospital para tratamento psiquiátrico?  Sim  Não

Se respondeu sim, quantas vezes? \_\_\_\_\_

### **Participação na organização**

22. Há quanto tempo frequenta a organização? \_\_\_\_\_

---

23. Em que programas/actividades/serviços da organização participa? (*assinale as opções que se adequarem*)

Actividades ocupacionais (ex. ateliers, artesanato, pintura, escrita, teatro e outras oficinas artísticas)

Actividades culturais (ex. visitas a museus ou exposições)

Treino de competências de vida diária

Psicoterapia de grupo

Reuniões comunitárias

Grupo de ajuda mútua (encontros de pares, i.e. outras pessoas com problemáticas de saúde mental, sem a  
presença dos profissionais)

Actividade desportiva de grupo, dinamizada pela organização

Actividade desportiva individual, conseguida através da organização

Residência comunitária

Apoio domiciliário

Suporte individual dos técnicos da organização, através de um Plano Individual de Recovery

Suporte individual dos técnicos da organização, através de um Plano Terapêutico

Outros programs/actividades/serviços? (especifique quais, por favor) \_\_\_\_\_

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# Questionário das Capacidades alcançadas em Saúde Mental Comunitária (QC-SMC)

ID-ORG

ID-PART

Data / /

## Instruções

*Este questionário procura conhecer as suas capacidades alcançadas através do suporte da organização na qual está a participar. Neste sentido, vai encontrar abaixo uma série de afirmações que representam possíveis capacidades que poderá ter alcançado no seu percurso dentro da organização.*

*Por favor, leia cada afirmação e reflecta se é adequada a sua experiência pessoal de ganhos conseguidos.*

*As opções de resposta são: **Conseguir totalmente; Conseguir parcialmente; Não conseguir muito; Não conseguir de todo.** Também tem uma opção de **Não se aplica à minha situação.***

*Escolha a opção que lhe parece mais adequada e assinale (com uma cruz ou um círculo) o número da escala que representa a sua resposta.*

*Por favor, tente responder a todas as perguntas. Caso não perceba alguma afirmação, peça apoio à equipa de investigação que irá estar consigo durante o preenchimento.*

## Que capacidades conseguiu alcançar através do suporte da Organização?

Através do suporte d\_ \_\_\_\_\_ consegui:

		Conseguir alcançar totalmente		Não conseguir alcançar de todo	
1	... ser sociável.	4	3	2	1
2	... ter esperança para o meu futuro.	4	3	2	1
3	... sentir-me respeitado/a pelos membros da comunidade.	4	3	2	1
4	... ter conhecimentos acerca da alimentação saudável.	4	3	2	1
5	... organizar-me nas tarefas de casa.	4	3	2	1
6	... participar nos eventos familiares.	4	3	2	1
7	... assistir a eventos públicos na área da saúde mental (ex. conferências).	4	3	2	1
8	... sentir-me integrado/a na comunidade.	4	3	2	1
9	... ter confiança em viver uma vida longa.	4	3	2	1
10	... ter oportunidades de realizar actividades de voluntariado.	4	3	2	1
11	... ter controlo sobre as actividades do dia a dia.	4	3	2	1
12	... ser sócio/a da organização.	4	3	2	1
13	... estar a vontade em espaços públicos.	4	3	2	1
14	... valorizar as minhas potencialidades.	4	3	2	1
15	... gerir o meu dinheiro.	4	3	2	1
16	... ter sentimentos de pertença à comunidade.	4	3	2	1
17	... ter autonomia em relação aos serviços de saúde mental.	4	3	2	1

Através do suporte d\_ \_\_\_\_\_ consegui:

		Consegui alcançar totalmente			Não consegui alcançar de todo
18	... estar alegre.	4	3	2	1
19	... ser autónomo/a na gestão da minha medicação.	4	3	2	1
20	... representar a organização ou os pares no sistema de saúde mental.	4	3	2	1
21	... tornar-me autónomo/a a nível financeiro.	4	3	2	1
22	... sentir-me aceite pela minha família.	4	3	2	1
23	... cuidar da minha condição física (ex. consultas médicas regulares, exames de rotina).	4	3	2	1
24	... participar num grupo de ajuda mútua de pares (i.e. com outras pessoas com experiência de doença mental, sem profissionais).	4	3	2	1
25	... apresentar comunicações em eventos públicos na área da saúde mental (ex. conferências).	4	3	2	1
26	... desfrutar do ambiente natural.	4	3	2	1
27	... tornar-me independente da minha família.	4	3	2	1
28	... ter poder de decisão sobre a minha vida.	4	3	2	1
29	... ter novos relacionamentos sociais.	4	3	2	1
30	... ser optimista.	4	3	2	1
31	... ocupar a mente com coisas úteis para a minha vida.	4	3	2	1
32	... interagir com os membros da comunidade.	4	3	2	1
33	... ser assertivo/a.	4	3	2	1
34	... aceder a uma habitação independente.	4	3	2	1
35	... ganhar alegria de viver.	4	3	2	1
36	... ter oportunidades de diversão.	4	3	2	1
37	... participar na defesa dos direitos das pessoas com experiência de doença mental.	4	3	2	1
38	... ter sentido de responsabilidade.	4	3	2	1
39	... confeccionar as minhas refeições.	4	3	2	1
40	... ter autoconfiança.	4	3	2	1
41	... sentir-me emocionalmente equilibrado/a.	4	3	2	1
42	... melhorar o relacionamento com a minha família.	4	3	2	1
43	... ser membro dos corpos sociais da organização.	4	3	2	1
44	... ser assíduo/a.	4	3	2	1
45	... ter consciência da minha condição física.	4	3	2	1
46	... estar relaxado/a.	4	3	2	1
47	... ter esperança de viver bem.	4	3	2	1
48	... ter auto-estima.	4	3	2	1

Data: \_\_\_\_/\_\_\_\_/\_\_\_\_

Código Identificação Organização: \_\_\_\_\_

Código Identificação Participante: \_\_\_\_\_

Nome Entrevistador/a: \_\_\_\_\_

### **Nota**

*Controlar os missings no protocolo.*

### **Forma de preenchimento**

Auto-preenchimento       Auxílio       Entrevistador

### **WHOQOL-BREF**

Freguesia \_\_\_\_\_ Concelho \_\_\_\_\_ Distrito \_\_\_\_\_

Está actualmente doente (fisicamente)?

Não       Sim      Qual doença \_\_\_\_\_      Há quanto tempo? \_\_\_\_\_

Regime de tratamento       Internamento       Consulta externa       Sem tratamento

### **Observações**

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# RAS-PT<sup>1</sup>

ID-ORG

ID-IND

Data / /

Abaixo encontra um conjunto de afirmações que descrevem sentimentos das pessoas sobre si próprias e sobre as suas vidas.

Por favor, leia cada uma delas com atenção e faça um círculo no número que melhor descreve até que ponto concorda ou discorda com a afirmação.

	Discordo totalmente	Discordo	Nem discordo nem concordo	Concordo	Concordo totalmente
1. O receio não me impede de viver como eu quero.	1	2	3	4	5
2. Eu consigo lidar com o que acontece na minha vida.	1	2	3	4	5
3. Eu gosto de mim próprio(a).	1	2	3	4	5
4. Se as pessoas realmente me conhecessem, gostariam de mim.	1	2	3	4	5
5. Eu tenho uma ideia daquilo que eu quero ser.	1	2	3	4	5
6. Alguma coisa de bom eventualmente acontecerá.	1	2	3	4	5
7. Tenho esperança acerca do meu futuro.	1	2	3	4	5
8. Continuo a ter novos interesses.	1	2	3	4	5
9. Consigo lidar com o stress.	1	2	3	4	5
10. Sei quando devo pedir ajuda.	1	2	3	4	5
11. Estou disposto(a) a pedir ajuda.	1	2	3	4	5
12. Eu peço ajuda quando preciso.	1	2	3	4	5
13. Tenho o desejo de ter sucesso.	1	2	3	4	5
14. Eu tenho o meu próprio plano para estar ou ficar bem.	1	2	3	4	5
15. Tenho objectivos na minha vida que quero alcançar.	1	2	3	4	5
16. Acredito que posso ir ao encontro dos meus objectivos pessoais actuais.	1	2	3	4	5
17. A minha vida tem um propósito.	1	2	3	4	5
18. Mesmo quando eu não me preocupo comigo, outros fazem-no.	1	2	3	4	5
19. Tenho pessoas com quem posso contar.	1	2	3	4	5
20. Mesmo quando não acredito em mim, outros acreditam.	1	2	3	4	5
21. É importante ter uma rede de amigos.	1	2	3	4	5
22. Lidar com a doença mental já não é o foco principal na minha vida.	1	2	3	4	5
23. Os meus sintomas interferem cada vez menos com a minha vida.	1	2	3	4	5
24. Cada vez que ocorrem, os meus sintomas parecem ser um problema por períodos cada vez mais curtos.	1	2	3	4	5



# BUES-PT<sup>1</sup>

ID-ORG ID-IND 

Data / /

Abaixo encontra afirmações relacionadas com perspectivas de vida e tomadas de decisão.

Não perca muito tempo em cada questão e seja verdadeiro(a) consigo mesmo(a), para que as respostas reflectam os seus verdadeiros sentimentos.

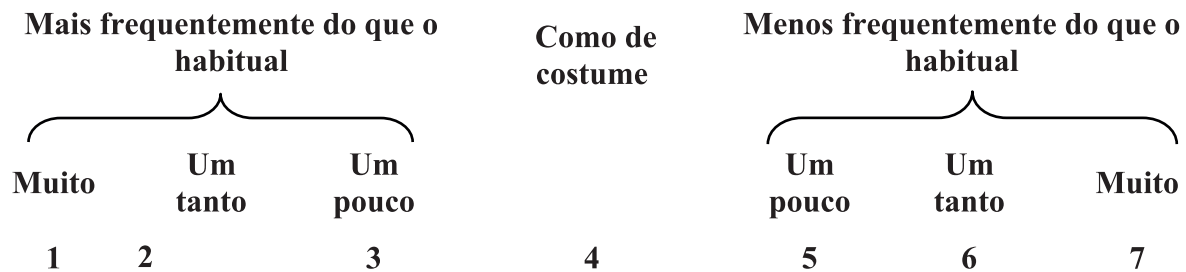
Assinale com um círculo o número que melhor corresponde ao que sente em relação à frase.

	Discordo totalmente	Discordo	Concordo	Concordo totalmente
1. Consigo determinar bastante bem o que acontecerá na minha vida.	4	3	2	1
2. As pessoas têm mais poder se se juntarem num grupo.	4	3	2	1
3. Ficar zangado(a) com alguma coisa nunca ajuda.	4	3	2	1
4. Tenho uma atitude positiva em relação a mim mesmo(a).	4	3	2	1
5. Sou, habitualmente, confiante com as decisões que tomo.	4	3	2	1
6. As pessoas não têm o direito de se zangar, só porque não gostam de alguma coisa.	4	3	2	1
7. A maioria dos infortúnios, na minha vida, teve a ver com má sorte.	4	3	2	1
8. Vejo-me como uma pessoa capaz.	4	3	2	1
9. Levantar ondas nunca leva a lado nenhum.	4	3	2	1
10. As pessoas a trabalhar em conjunto podem influenciar a sua comunidade.	4	3	2	1
11. Habitualmente, sou capaz de ultrapassar barreiras.	4	3	2	1
12. Sou, geralmente, optimista em relação ao futuro.	4	3	2	1
13. Quando faço planos, estou quase certo (a) de ser capaz de os fazer resultar.	4	3	2	1
14. Normalmente sinto-me sozinho(a).	4	3	2	1
15. Os especialistas estão em melhor posição para decidir o que as pessoas devem fazer ou aprender.	4	3	2	1
16. Sou capaz de fazer as coisas tão bem como a maioria das pessoas.	4	3	2	1
17. Geralmente, concretizo o que me proponho a fazer.	4	3	2	1
18. As pessoas devem tentar viver as suas vidas como querem.	4	3	2	1
19. A maior parte do tempo, sinto-me sem poder.	4	3	2	1
20. Quando não tenho a certeza sobre alguma coisa, normalmente, sigo o resto do grupo.	4	3	2	1
21. Sinto que sou uma pessoa de valor tanto como qualquer outra.	4	3	2	1
22. As pessoas têm o direito de tomar as suas próprias decisões, mesmo que sejam más decisões.	4	3	2	1
23. Sinto que tenho algumas boas qualidades.	4	3	2	1
24. Frequentemente, um problema pode ser resolvido agindo.	4	3	2	1
25. Trabalhar com os outros, na minha comunidade, pode ajudar a mudar as coisas para melhor.	4	3	2	1





- Q2.** As últimas dez questões perguntaram sobre sentimentos que podem ter ocorrido durante os últimos 30 dias. Tomados juntos, esses sentimentos ocorreram Mais frequentemente nos últimos 30 dias do que é habitual para você, como de costume, ou menos frequentemente do que o habitual? (Se você nunca teve quaisquer desses sentimentos nos últimos 30 dias, circule a opção de resposta “4.”)



As próximas questões são sobre como esses sentimentos podem ter afetado você nos últimos 30 dias. Você não precisa respondê-las se respondeu “Nunca” para **todas** as dez questões sobre como você se sentiu.

- Q3.** Durante os últimos 30 dias, quantos dias você esteve totalmente incapaz de trabalhar ou realizar as suas atividades habituais por causa desses sentimentos?

\_\_\_\_\_ (Número de dias)

- Q4.** Sem contar os dias que você relatou em resposta a **Q3**, quantos dias nos últimos 30 você foi capaz de fazer somente metade ou menos do que normalmente seria capaz de fazer, por causa desses sentimentos?

\_\_\_\_\_ (Número de dias)

- Q5.** Durante os últimos 30 dias, quantas vezes você consultou um médico ou outro profissional de saúde por causa desses sentimentos?

\_\_\_\_\_ (Número de vezes)

- |            |                     |                               |                       |                 |              |
|------------|---------------------|-------------------------------|-----------------------|-----------------|--------------|
|            | <b>O tempo todo</b> | <b>A maior parte do tempo</b> | <b>Parte do tempo</b> | <b>Um pouco</b> | <b>Nunca</b> |
|            | _____               | _____                         | _____                 | _____           | _____        |
| <b>Q6.</b> | 1                   | 2                             | 3                     | 4               | 5            |
- Durante os últimos 30 dias, com que frequência os seus problemas de saúde física foram a causa principal desses sentimentos?

**Obrigado por completar este questionário.**

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### **Acknowledgements**

Translation of this document was performed on behalf of the World Health Organization Composite International Diagnostic Interview Advisory Committee by Yuan-Pang Wang, MD, PhD, Clarice Gorenstein, PhD, and Laura Helena Andrade, MD, PhD, of the Institute and Department of Psychiatry, Medical School of University of Sao Paulo, Brazil; and Maria Carmen Viana, MD, PhD, of the Department of Social Medicine, Federal University of Espírito Santo, Brazil.

# WHOQOL-BREF



**ORGANIZAÇÃO MUNDIAL DE SAÚDE**



**FACULDADE DE MEDICINA DA UNIVERSIDADE DE COIMBRA**

Coordenador: Prof. Doutor Adriano Vaz Serra (adrianovs@netvisao.pt)



**FACULDADE DE PSICOLOGIA E DE CIÊNCIAS DA EDUCAÇÃO DA UNIVERSIDADE DE COIMBRA**

Coordenadora: Prof. Doutora Maria Cristina Canavarro (mccanavarro@fpce.uc.pt)

	Equações para calcular a pontuação dos domínios	Resultados	Resultados transformados	
			4-20	0-100
<b>Domínio 1</b>	$(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/>			
<b>Domínio 2</b>	$Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$ <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/>			
<b>Domínio 3</b>	$Q20 + Q21 + Q22$ <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/>			
<b>Domínio 4</b>	$Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/>			

## DADOS PESSOAIS

**A1 Idade**  anos

**A2 Data de Nascimento** \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**A3 Sexo**  Masculino  
 Feminino

<b>A4 Escolaridade</b>		
Não sabe ler nem escrever		
Sabe ler e/ou escrever		
1 <sup>o</sup> -4 <sup>o</sup> anos		
5 <sup>o</sup> -6 <sup>o</sup> anos		
7 <sup>o</sup> -9 <sup>o</sup> anos		
10 <sup>o</sup> -12 <sup>o</sup> anos		
Estudos Universitários		
Formação pós-graduada		

**A5 Profissão**

**A6.1 Freguesia**   
**A6.2 Concelho**   
**A6.3 Distrito**

<b>A7 Estado Civil</b>		
Solteiro(a)		
Casado(a)		
União de facto		
Separado(a)		
Divorciado(a)		
Viúvo(a)		

**B1a** Está actualmente doente? Sim  Não

**B1b** Que doença é que tem? \_\_\_\_\_

**B2** Há quanto tempo? \_\_\_\_\_

**B3** Regime de tratamento? Internamento  Consulta Externa  Sem tratamento

### C. Forma de administração do questionário

1. Auto-administrado
2. Assistido pelo entrevistador
3. Administrado pelo entrevistador

### D. Tem alguns comentários a fazer a este estudo?

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**OBRIGADO PELA SUA AJUDA!**

## Instruções

Este questionário procura conhecer a sua qualidade de vida, saúde, e outras áreas da sua vida.

Por favor, responda a todas as perguntas. Se não tiver a certeza da resposta a dar a uma pergunta, escolha a que lhe parecer mais apropriada. Esta pode muitas vezes ser a resposta que lhe vier primeiro à cabeça.

Por favor, tenha presente os seus padrões, expectativas, alegrias e preocupações. Pedimos-lhe que tenha em conta a sua vida nas **duas últimas semanas**.

Por exemplo, se pensar nestas duas últimas semanas, pode ter que responder à seguinte pergunta:

	Nada	Pouco	Moderadamente	Bastante	Completamente
Recebe das outras pessoas o tipo de apoio que necessita?	1	2	3	4	5

Deve pôr um círculo à volta do número que melhor descreve o apoio que recebeu das outras pessoas nas duas últimas semanas. Assim, marcaria o número 4 se tivesse recebido bastante apoio, ou o número 1 se não tivesse tido nenhum apoio dos outros nas duas últimas semanas.

**Por favor leia cada pergunta, veja como se sente a respeito dela, e ponha um círculo à volta do número da escala para cada pergunta que lhe parece que dá a melhor resposta.**

		Muito Má	Má	Nem Boa Nem Má	Boa	Muito Boa
<b>1 (G1)</b>	Como avalia a sua qualidade de vida?	1	2	3	4	5

		Muito Insatisfeito	Insatisfeito	Nem satisfeito nem insatisfeito	Satisfeito	Muito Satisfeito
<b>2 (G4)</b>	Até que ponto está satisfeito(a) com a sua saúde?	1	2	3	4	5

As perguntas seguintes são para ver até que ponto sentiu certas coisas nas duas últimas semanas.

		Nada	Pouco	Nem muito nem pouco	Muito	Muitíssimo
<b>3 (F1.4)</b>	Em que medida as suas dores (físicas) o(a) impedem de fazer o que precisa de fazer?	1	2	3	4	5
<b>4 (F11.3)</b>	Em que medida precisa de cuidados médicos para fazer a sua vida diária?	1	2	3	4	5
<b>5 (F4.1)</b>	Até que ponto gosta da vida?	1	2	3	4	5
<b>6 (F24.2)</b>	Em que medida sente que a sua vida tem sentido?	1	2	3	4	5
<b>7 (F5.3)</b>	Até que ponto se consegue concentrar?	1	2	3	4	5
<b>8 (F16.1)</b>	Em que medida se sente em segurança no seu dia-a-dia?	1	2	3	4	5
<b>9 (F22.1)</b>	Em que medida é saudável o seu ambiente físico?	1	2	3	4	5

As seguintes perguntas são para ver **até que ponto** experimentou ou foi capaz de fazer certas coisas nas duas últimas semanas.

		Nada	Pouco	Moderadamente	Bastante	Completamente
<b>10 (F2.1)</b>	Tem energia suficiente para a sua vida diária?	1	2	3	4	5
<b>11 (F7.1)</b>	É capaz de aceitar a sua aparência física?	1	2	3	4	5
<b>12 (F18.1)</b>	Tem dinheiro suficiente para satisfazer as suas necessidades?	1	2	3	4	5
<b>13 (F20.1)</b>	Até que ponto tem fácil acesso às informações necessárias para organizar a sua vida diária?	1	2	3	4	5
<b>14 (F21.1)</b>	Em que medida tem oportunidade para realizar actividades de lazer?	1	2	3	4	5

		Muito Má	Má	Nem boa nem má	Boa	Muito Boa
<b>15 (F9.1)</b>	Como avaliaria a sua mobilidade [capacidade para se movimentar e deslocar por si próprio(a)]?	1	2	3	4	5

As perguntas que se seguem destinam-se a avaliar se se sentiu **bem ou satisfeito(a)** em relação a vários aspectos da sua vida nas duas últimas semanas.

		Muito Insatisfeito	Insatisfeito	Nem satisfeito nem insatisfeito	Satisfeito	Muito Satisfeito
<b>16 (F3.3)</b>	Até que ponto está satisfeito(a) com o seu sono?	1	2	3	4	5
<b>17 (F10.3)</b>	Até que ponto está satisfeito(a) com a sua capacidade para desempenhar as actividades do seu dia-a-dia?	1	2	3	4	5
<b>18 (F12.4)</b>	Até que ponto está satisfeito(a) com a sua capacidade de trabalho?	1	2	3	4	5
<b>19 (F6.3)</b>	Até que ponto está satisfeito(a) consigo próprio(a)?	1	2	3	4	5
<b>20 (F13.3)</b>	Até que ponto está satisfeito(a) com as suas relações pessoais?	1	2	3	4	5
<b>21 (F15.3)</b>	Até que ponto está satisfeito(a) com a sua vida sexual?	1	2	3	4	5
<b>22 (F14.4)</b>	Até que ponto está satisfeito(a) com o apoio que recebe dos seus amigos?	1	2	3	4	5
<b>23 (F17.3)</b>	Até que ponto está satisfeito(a) com as condições do lugar em que vive?	1	2	3	4	5
<b>24 (F19.3)</b>	Até que ponto está satisfeito(a) com o acesso que tem aos serviços de saúde?	1	2	3	4	5
<b>25 (F23.3)</b>	Até que ponto está satisfeito(a) com os transportes que utiliza?	1	2	3	4	5

As perguntas que se seguem referem-se à **frequência** com que sentiu ou experimentou certas coisas nas duas últimas semanas.

		Nunca	Poucas vezes	Algumas vezes	Frequentemente	Sempre
<b>26 (F8.1)</b>	Com que frequência tem sentimentos negativos, tais como tristeza, desespero, ansiedade ou depressão?	1	2	3	4	5

**Annex VIII – Authorization for Scale Use**





**Re: Instrumento de avaliação WHOQOL-Bref**

Cláudia Melo [claudiasmelosilva@gmail.com]

**Sent:** Wednesday, November 19, 2014 8:17 AM**To:** Beatrice Ilaria Mariasole Sacchetto**Attachments:** 2007\_WHOQOL\_Bref\_Instrumen~1.pdf (6 MB) ; Estudos psicométricos - V~1.pdf (123 KB) ; Explicação\_cotação.doc (23 KB) ; Ref-values-final-document~1.docx (52 KB) ; WHOQOL-BREF.zip (206 KB)

Cara Dra. Beatrice Sacchetto,

Na sequência do pedido efectuado, em anexo envio o material relativo ao WHOQOL-Bref, nomeadamente:

- a versão para português de Portugal do instrumento WHOQOL-Bref;
- manual de aplicação e cotação;
- sintaxe para utilização no pacote estatístico SPSS.

Informação adicional poderá ser encontrada em

<http://www.fpce.uc.pt/saude/qv.htm>

Com os melhores cumprimentos,

Cláudia Melo. Pelo Grupo Português de Avaliação da Qualidade de Vida



**Annex IX – CQ-CMH-104 version for the Content Validity**



## Questionário de Capacidades - Saúde Mental Comunitária (QC-SMC)

### Avaliação da validade de conteúdo

**Pedimos que por cada item indique:**

- A relevância numa escala Likert de 5 pontos (de nada relevante a muito relevante);

- Eventuais observações e/ou sugestões de alteração.

#### 1. VIDA

A participação neste serviço permitiu-me...

	Nada relevante					Muito relevante					Observações
1 ... ter esperança de viver bem até ser velho(a).	1	2	3	4	5						
2 ... ter melhor qualidade de vida.	1	2	3	4	5						

#### 2. SAÚDE - física e mental

A participação neste serviço permitiu-me...

	Nada relevante					Muito relevante					Observações
3 ... estar mais activo(a).	1	2	3	4	5						
4 ... estar mais relaxado(a).	1	2	3	4	5						
5 ... ter uma vida mais saudável.	1	2	3	4	5						
6 ... ter mais consciência da minha condição física.	1	2	3	4	5						
7 ... cuidar melhor da minha condição física (ex. consultas médicas regulares, realização de exames de rotina, etc.)	1	2	3	4	5						
8 ... ter mais conhecimentos sobre alimentação saudável.	1	2	3	4	5						
9 ... melhorar a qualidade da minha alimentação.	1	2	3	4	5						
10 ... praticar mais actividade física (por ex. caminhadas, exercício físico, actividade desportiva).	1	2	3	4	5						
11 ... ter mais informação acerca das consequências do consumo de tabaco.	1	2	3	4	5						
12 ... reduzir o consumo de tabaco.	1	2	3	4	5						
13 ... ter mais controlo sobre alguns aspectos da minha doença mental.	1	2	3	4	5						
14 ... diminuir as preocupações com a doença mental.	1	2	3	4	5						
15 ... ter menos internamentos.	1	2	3	4	5						
16 ... manter a medicação estabilizada.	1	2	3	4	5						

### 3. INTEGRIDADE FÍSICA

A participação neste serviço permitiu-me...

						Observações	
	Nada relevante		Muito relevante				
17	...	1	2	3	4	5	
17	... não ter receio de ser vítima de violência.	1	2	3	4	5	
18	...	1	2	3	4	5	
18	... sentir-me mais seguro(a) em utilizar os transportes públicos.	1	2	3	4	5	
19	...	1	2	3	4	5	
19	... estar mais a vontade em espaços públicos	1	2	3	4	5	
20	...	1	2	3	4	5	
20	... sentir-me mais protegido(a) no local onde vivo.	1	2	3	4	5	
21	...	1	2	3	4	5	
21	... não ter receio de ser vítima de abuso sexual.	1	2	3	4	5	
22	...	1	2	3	4	5	
22	... sentir-me livre para viver a minha sexualidade.	1	2	3	4	5	

### 4. SENTIDO, IMAGINAÇÃO E PENSAMENTO

A participação neste serviço permitiu-me...

						Observações	
	Nada relevante		Muito relevante				
23	...	1	2	3	4	5	
23	... valorizar mais as minhas capacidades.	1	2	3	4	5	
24	...	1	2	3	4	5	
24	... tornar-me mais culto(a).	1	2	3	4	5	
25	...	1	2	3	4	5	
25	... estar mais criativo(a).	1	2	3	4	5	
26	...	1	2	3	4	5	
26	... raciocinar melhor.	1	2	3	4	5	
27	...	1	2	3	4	5	
27	... desenvolver a minha capacidade intelectual.	1	2	3	4	5	
28	...	1	2	3	4	5	
28	... ter pensamentos mais assertivos.	1	2	3	4	5	
29	...	1	2	3	4	5	
29	... ter mais sentido de responsabilidade.	1	2	3	4	5	
30	...	1	2	3	4	5	
30	... ocupar a mente com coisas úteis para a minha vida.	1	2	3	4	5	
31	...	1	2	3	4	5	
31	... aumentar a minha escolaridade.	1	2	3	4	5	

### 5. EMOÇÕES, SENTIMENTOS E RELAÇÕES AFETIVAS

A participação neste serviço permitiu-me...

						Observações	
	Nada relevante		Muito relevante				
32	...	1	2	3	4	5	
32	... ganhar alegria de viver.	1	2	3	4	5	
33	...	1	2	3	4	5	
33	... sentir-me emocionalmente mais equilibrado(a).	1	2	3	4	5	
34	...	1	2	3	4	5	
34	... ter mais auto-confiança.	1	2	3	4	5	
35	...	1	2	3	4	5	
35	... ter mais auto-estima.	1	2	3	4	5	
36	...	1	2	3	4	5	
36	... ter mais sentimentos de empatia.	1	2	3	4	5	
37	...	1	2	3	4	5	
37	... ter novos princípios morais.	1	2	3	4	5	
38	...	1	2	3	4	5	
38	... estar mais optimista.	1	2	3	4	5	
39	...	1	2	3	4	5	
39	... sentir-me mais motivado(a) para me levantar todos os dias.	1	2	3	4	5	

		Nada relevante					Muito relevante	Observações
40	... ter mais esperança para o meu futuro.	1	2	3	4	5		
41	... sentir-me bem sozinho(a) em casa.	1	2	3	4	5		
42	... ter um(a) namorado(a).	1	2	3	4	5		
43	... melhorar o relacionamento com os(as) amigos(as).	1	2	3	4	5		
44	... melhorar o relacionamento com os membros da família.	1	2	3	4	5		
45	... participar mais nos eventos familiares.	1	2	3	4	5		
46	... que a minha família passasse a aceitar-me melhor.	1	2	3	4	5		
47	... tornar-me mais independente da minha família.	1	2	3	4	5		
48	... ter maior autonomia em relação aos serviços de saúde mental.	1	2	3	4	5		

## 6. RAZÃO PRÁTICA, REFLEXÃO CRÍTICA

A participação neste serviço permitiu-me...

		Nada relevante					Muito relevante	Observações
49	... ter planos para o futuro.	1	2	3	4	5		
50	... ter mais poder de decisão sobre a minha vida.	1	2	3	4	5		
51	... ter mais capacidade de resolver situações de vida.	1	2	3	4	5		
52	... ter uma rotina satisfatória.	1	2	3	4	5		
53	... ser mais assíduo(a).	1	2	3	4	5		
54	... ser mais disciplinado(a).	1	2	3	4	5		
55	... cumprir os meus compromissos.	1	2	3	4	5		
56	... adquirir uma nova perspectiva sobre a doença mental.	1	2	3	4	5		
57	... ter mais autonomia na gestão da minha medicação.	1	2	3	4	5		
58	... aprender a organizar-me nas tarefas de casa.	1	2	3	4	5		
59	... aprender a confeccionar as minhas refeições.	1	2	3	4	5		
60	... aprender a poupar dinheiro.	1	2	3	4	5		
61	... obter bons resultados nas tarefas propostas pelos serviços.	1	2	3	4	5		

## 7. AFILIAÇÃO, INTERAÇÕES SOCIAIS E COMUNITÁRIAS

A participação neste serviço permitiu-me...

	Nada relevante					Muito relevante					Observações
	1	2	3	4	5	1	2	3	4	5	
62	... ter sentimentos de pertença à comunidade.										
63	... sentir-me mais integrado(a) na comunidade.										
64	... interagir mais com os membros da comunidade.										
65	... sentir-me mais respeitado(a) pelos membros da comunidade.										
66	... utilizar mais os locais na comunidade (mercearia, cinema, igreja, cabeleireiro, banco, etc.).										
67	... ter novos relacionamentos sociais.										
68	... conhecer outras pessoas que não têm doença mental.										
69	... ser mais sociável.										
70	... melhorar o relacionamento com os vizinhos.										
71	... ter oportunidade de dar apoio aos meus pares.										
72	... aprender a trabalhar em equipa.										

## 8. OUTRAS ESPÉCIES

A participação neste serviço permitiu-me...

	Nada relevante					Muito relevante					Observações
	1	2	3	4	5	1	2	3	4	5	
73	... ter oportunidades de cuidar de outras espécies (animais, plantas).										
74	... adquirir mais respeito pela natureza.										
75	... desfrutar mais do ambiente natural.										

## 9. LAZER E TEMPO LIVRE

A participação neste serviço permitiu-me...

	Nada relevante					Muito relevante					Observações
	1	2	3	4	5	1	2	3	4	5	
76	... viver a vida de modo mais pleno.										
77	... apreciar mais as actividades recreativas.										
78	... estar mais alegre.										
79	... divertir-me com os(as) colegas e amigos(as).										



## 10. CONTROLO DO PRÓPRIO AMBIENTE – material, dos recursos; político e cívico

A participação neste serviço permitiu-me...

		Nada relevante					Muito relevante					Observações
		1	2	3	4	5	1	2	3	4	5	
80	... ter a liberdade de me expressar como entender.	1	2	3	4	5						
81	... ter mais poder sobre a minha vida.	1	2	3	4	5						
82	... ter mais controlo sobre os acontecimentos de vida.	1	2	3	4	5						
83	... participar na definição dos meus objectivos individuais.	1	2	3	4	5						
84	... aceder ao que é necessário para poder votar.	1	2	3	4	5						
85	... ter acesso à apoio jurídico.	1	2	3	4	5						
86	... tornar-me mais autónomo(a) a nível financeiro.	1	2	3	4	5						
87	... ter oportunidades de emprego.	1	2	3	4	5						
88	... ter oportunidades de valorizar-me profissionalmente.	1	2	3	4	5						
89	... deixar de viver no hospital.	1	2	3	4	5						
90	... aceder a uma casa com boas condições.	1	2	3	4	5						
91	... sair da casa dos pais.	1	2	3	4	5						
92	... poder pagar a renda da minha casa.	1	2	3	4	5						
93	... conhecer melhor a cidade onde moro.	1	2	3	4	5						
94	... contribuir para a organização e realização das actividades do serviço.	1	2	3	4	5						
95	... ser sócio(a) da instituição/organização.	1	2	3	4	5						
96	... ser membro dos órgãos sociais da instituição/organização.	1	2	3	4	5						
97	... assistir em conferências e workshops na área da saúde mental.	1	2	3	4	5						
98	... participar em eventos públicos ou de formação.	1	2	3	4	5						
99	... apresentar comunicações em conferências e workshops.	1	2	3	4	5						
100	... representar a organização ou os pares em órgãos especializados na área da saúde mental.	1	2	3	4	5						
101	... participar no grupo de ajuda mútua de pares.	1	2	3	4	5						
102	... ter oportunidade de trocar experiências com os meus pares.	1	2	3	4	5						
103	... promover a defesa dos direitos humanos das pessoas com doença mental.	1	2	3	4	5						
104	... lutar pela defesa dos meus interesses.	1	2	3	4	5						



**Annex X – ACQ-CMH-98 version for EFA**



# Questionário das Capacidades para o contexto da Saúde Mental Comunitária (QC-SMC)

ID-ORG

ID-PART

Data / /

## Instruções

*Este questionário procura conhecer as suas capacidades alcançadas através do suporte da organização na qual está a participar. Neste sentido, vai encontrar abaixo uma série de afirmações que representam possíveis capacidades que poderá ter alcançado no seu percurso dentro da organização.*

*Por favor, leia cada afirmação e reflita se é adequada a sua experiência pessoal de ganhos conseguidos.*

*As opções de resposta são: **Conseguí totalmente; Conseguí parcialmente; Não conseguí muito; Não conseguí de todo.** Também tem uma opção de **Não se aplica à minha situação.***

*Escolha a opção que lhe parece mais adequada e assinale (com uma cruz ou um círculo) o número da escala que representa a sua resposta.*

*Por favor, tente responder a todas as perguntas. Caso não perceba alguma afirmação, peça apoio à equipa de investigação que irá estar consigo durante o preenchimento.*

## Que capacidades conseguiu alcançar através do suporte da Organização?

Através do suporte d\_ \_\_\_\_\_ consegui:

	Conseguí totalmente	Conseguí parcialmente	Não conseguí muito	Não conseguí de todo	Não se aplica à minha situação
1. ... praticar actividade física (ex. caminhadas, exercício físico, actividade desportiva).	4	3	2	1	0
2. ... ser sociável.	4	3	2	1	0
3. .... cumprir os meus compromissos.	4	3	2	1	0
4. ... sentir-me seguro/a em utilizar os transportes públicos.	4	3	2	1	0
5. ... aumentar a minha escolaridade.	4	3	2	1	0
6. ... ter esperança para o meu futuro.	4	3	2	1	0
7. ... sentir-me respeitado/a pelos membros da comunidade.	4	3	2	1	0
8. ... utilizar os locais na comunidade (ex. mercearia, cinema, igreja, cabeleireiro, banco).	4	3	2	1	0
9. ... ter oportunidade de dar apoio aos meus pares (i.e. outras pessoas com experiência de doença mental).	4	3	2	1	0
10. ... ter conhecimentos acerca da alimentação saudável.	4	3	2	1	0
11. ... organizar-me nas tarefas de casa.	4	3	2	1	0
12. ... conhecer pessoas que não têm doença mental.	4	3	2	1	0
13. ... partilhar experiências com os meus pares (i.e. outras pessoas com experiência de doença mental).	4	3	2	1	0
14. ... conhecer a cidade onde eu moro.	4	3	2	1	0

Através do suporte d\_ \_\_\_\_\_ consegui:

	Conseguí totalmente	Conseguí parcialmente	Não conseguí muito	Não conseguí de todo	Não se aplica à minha situação
15. ... ter um/a namorado/a.	4	3	2	1	0
16. ... participar nos eventos familiares.	4	3	2	1	0
17. ... ter uma vida saudável.	4	3	2	1	0
18. ... ter acesso ao apoio jurídico quando necessário.	4	3	2	1	0
19. ... assistir a eventos públicos na área da saúde mental (ex. conferências).	4	3	2	1	0
20. ... sentir-me integrado/a na comunidade.	4	3	2	1	0
21. ... planear o meu futuro.	4	3	2	1	0
22. ... reduzir o número de internamentos.	4	3	2	1	0
23. ... ter confiança em viver uma vida longa.	4	3	2	1	0
24. ... ter oportunidades de realizar actividades de voluntariado.	4	3	2	1	0
25. ... ter controlo sobre as actividades do dia a dia.	4	3	2	1	0
26. ... sentir-me bem sozinho/a em casa.	4	3	2	1	0
27. ... contribuir para organizar as actividades da organização.	4	3	2	1	0
28. ... ter controlo sobre alguns aspectos da minha doença mental.	4	3	2	1	0
29. ... ser sócio/a da organização.	4	3	2	1	0
30. ... adquirir respeito pela natureza.	4	3	2	1	0
31. ... estar a vontade em espaços públicos.	4	3	2	1	0
32. ... valorizar as minhas potencialidades.	4	3	2	1	0
33. ... deixar de viver numa estrutura hospitalar.	4	3	2	1	0
34. ... gerir o meu dinheiro.	4	3	2	1	0
35. ... ter sentimentos de pertença à comunidade.	4	3	2	1	0
36. ... melhorar a qualidade da minha alimentação.	4	3	2	1	0
37. ... ter autonomia em relação aos serviços de saúde mental.	4	3	2	1	0
38. ... ter capacidade de resolver situações de vida.	4	3	2	1	0
39. ... estar alegre.	4	3	2	1	0
40. ... ser autónomo/a na gestão da minha medicação.	4	3	2	1	0
41. ... tornar-me uma pessoa informada.	4	3	2	1	0
42. ... representar a organização ou os pares no sistema de saúde mental.	4	3	2	1	0
43. ... tornar-me autónomo/a a nível financeiro.	4	3	2	1	0
44. ... ter qualidade de vida.	4	3	2	1	0
45. ... sentir-me aceite pela minha família.	4	3	2	1	0
46. ... melhorar o relacionamento com os/as amigos/as.	4	3	2	1	0
47. ... sentir-me motivado/a para me levantar todos os dias.	4	3	2	1	0
48. ... cuidar da minha condição física (ex. consultas médicas regulares, exames de rotina).	4	3	2	1	0

Através do suporte d\_ \_\_\_\_\_ conseguiu:

	Conseguí totalmente	Conseguí parcialmente	Não conseguí muito	Não conseguí de todo	Não se aplica à minha situação
49. ... reduzir o consumo de tabaco.	4	3	2	1	0
50. ... não ter receio de ser vítima de abuso sexual.	4	3	2	1	0
51. ... participar num grupo de ajuda mútua de pares (i.e. com outras pessoas com experiência de doença mental, sem profissionais).	4	3	2	1	0
52. ... apresentar comunicações em eventos públicos na área da saúde mental (ex. conferências).	4	3	2	1	0
53. ... desfrutar do ambiente natural.	4	3	2	1	0
54. ... melhorar o relacionamento com os vizinhos.	4	3	2	1	0
55. ... tornar-me independente da minha família.	4	3	2	1	0
56. ... ter oportunidades de cuidar de outras espécies (animais, plantas).	4	3	2	1	0
57. ... ter poder de decisão sobre a minha vida.	4	3	2	1	0
58. ... diminuir as preocupações com a doença mental.	4	3	2	1	0
59. ... sentir-me livre para viver a minha sexualidade.	4	3	2	1	0
60. ... ajustar a minha medicação.	4	3	2	1	0
61. ... ter novos relacionamentos sociais.	4	3	2	1	0
62. ... ser optimista.	4	3	2	1	0
63. ... ter informação acerca das consequências do consumo de tabaco.	4	3	2	1	0
64. ... ocupar a mente com coisas úteis para a minha vida.	4	3	2	1	0
65. ... pagar a renda da minha casa.	4	3	2	1	0
66. ... interagir com os membros da comunidade.	4	3	2	1	0
67. ... ser assertivo/a.	4	3	2	1	0
68. ... ter a liberdade para me expressar como entender.	4	3	2	1	0
69. ... aceder a uma habitação independente.	4	3	2	1	0
70. ... ganhar alegria de viver.	4	3	2	1	0
71. ... ter oportunidades de diversão.	4	3	2	1	0
72. ... sentir-me protegido/a no local onde vivo.	4	3	2	1	0
73. ... deixar de viver com os familiares.	4	3	2	1	0
74. ... expressar a minha criatividade.	4	3	2	1	0
75. ... aceder ao que é necessário para poder votar.	4	3	2	1	0
76. ... aprender a trabalhar em equipa.	4	3	2	1	0
77. ... estar activo/a.	4	3	2	1	0
78. ... participar na defesa dos direitos das pessoas com experiência de doença mental.	4	3	2	1	0
79. ... ter sentido de responsabilidade.	4	3	2	1	0
80. ... desenvolver a minha capacidade intelectual.	4	3	2	1	0

Através do suporte d\_ \_\_\_\_\_ consegui:

	Conseguí totalmente	Conseguí parcialmente	Não conseguí muito	Não conseguí de todo	Não se aplica à minha situação
81. ... não ter receio de ser vítima de violência.	4	3	2	1	0
82. ... confeccionar as minhas refeições.	4	3	2	1	0
83. ... ter uma rotina satisfatória.	4	3	2	1	0
84. ... ter autoconfiança.	4	3	2	1	0
85. ... aproveitar actividades recreativas.	4	3	2	1	0
86. ... sentir-me emocionalmente equilibrado/a.	4	3	2	1	0
87. ... ter poder sobre a minha vida.	4	3	2	1	0
88. ... melhorar o relacionamento com a minha família.	4	3	2	1	0
89. ... ser membro dos corpos sociais da organização.	4	3	2	1	0
90. ... ser assíduo/a.	4	3	2	1	0
91. ... ter consciência da minha condição física.	4	3	2	1	0
92. ... estar relaxado/a.	4	3	2	1	0
93. ... ter oportunidades de emprego.	4	3	2	1	0
94. ... ter esperança de viver bem.	4	3	2	1	0
95. ... ter sentimentos de empatia.	4	3	2	1	0
96. ... ter oportunidades de me valorizar profissionalmente.	4	3	2	1	0
97. ... ter auto-estima.	4	3	2	1	0
98. ... definir os meus objectivos.	4	3	2	1	0



**Annex XI – ACQ-CMH-48 for CFA**



# Questionário das Capacidades alcançadas em Saúde Mental Comunitária (QC-SMC)

ID-ORG

ID-PART

Data / /

## Instruções

*Este questionário procura conhecer as suas capacidades alcançadas através do suporte da organização na qual está a participar. Neste sentido, vai encontrar abaixo uma série de afirmações que representam possíveis capacidades que poderá ter alcançado no seu percurso dentro da organização.*

*Por favor, leia cada afirmação e reflecta se é adequada a sua experiência pessoal de ganhos conseguidos.*

*As opções de resposta são: **Conseguir totalmente; Conseguir parcialmente; Não conseguir muito; Não conseguir de todo.** Também tem uma opção de **Não se aplica à minha situação.***

*Escolha a opção que lhe parece mais adequada e assinale (com uma cruz ou um círculo) o número da escala que representa a sua resposta.*

*Por favor, tente responder a todas as perguntas. Caso não perceba alguma afirmação, peça apoio à equipa de investigação que irá estar consigo durante o preenchimento.*

## Que capacidades conseguiu alcançar através do suporte da Organização?

Através do suporte d\_ \_\_\_\_\_ consegui:

		Conseguir alcançar totalmente		Não conseguir alcançar de todo	
1	... ser sociável.	4	3	2	1
2	... ter esperança para o meu futuro.	4	3	2	1
3	... sentir-me respeitado/a pelos membros da comunidade.	4	3	2	1
4	... ter conhecimentos acerca da alimentação saudável.	4	3	2	1
5	... organizar-me nas tarefas de casa.	4	3	2	1
6	... participar nos eventos familiares.	4	3	2	1
7	... assistir a eventos públicos na área da saúde mental (ex. conferências).	4	3	2	1
8	... sentir-me integrado/a na comunidade.	4	3	2	1
9	... ter confiança em viver uma vida longa.	4	3	2	1
10	... ter oportunidades de realizar actividades de voluntariado.	4	3	2	1
11	... ter controlo sobre as actividades do dia a dia.	4	3	2	1
12	... ser sócio/a da organização.	4	3	2	1
13	... estar a vontade em espaços públicos.	4	3	2	1
14	... valorizar as minhas potencialidades.	4	3	2	1
15	... gerir o meu dinheiro.	4	3	2	1
16	... ter sentimentos de pertença à comunidade.	4	3	2	1
17	... ter autonomia em relação aos serviços de saúde mental.	4	3	2	1

Através do suporte d\_ \_\_\_\_\_ consegui:

	Consegui alcançar totalmente			Não consegui alcançar de todo
18 ... estar alegre.	4	3	2	1
19 ... ser autónomo/a na gestão da minha medicação.	4	3	2	1
20 ... representar a organização ou os pares no sistema de saúde mental.	4	3	2	1
21 ... tornar-me autónomo/a a nível financeiro.	4	3	2	1
22 ... sentir-me aceite pela minha família.	4	3	2	1
23 ... cuidar da minha condição física (ex. consultas médicas regulares, exames de rotina).	4	3	2	1
24 ... participar num grupo de ajuda mútua de pares (i.e. com outras pessoas com experiência de doença mental, sem profissionais).	4	3	2	1
25 ... apresentar comunicações em eventos públicos na área da saúde mental (ex. conferências).	4	3	2	1
26 ... desfrutar do ambiente natural.	4	3	2	1
27 ... tornar-me independente da minha família.	4	3	2	1
28 ... ter poder de decisão sobre a minha vida.	4	3	2	1
29 ... ter novos relacionamentos sociais.	4	3	2	1
30 ... ser optimista.	4	3	2	1
31 ... ocupar a mente com coisas úteis para a minha vida.	4	3	2	1
32 ... interagir com os membros da comunidade.	4	3	2	1
33 ... ser assertivo/a.	4	3	2	1
34 ... aceder a uma habitação independente.	4	3	2	1
35 ... ganhar alegria de viver.	4	3	2	1
36 ... ter oportunidades de diversão.	4	3	2	1
37 ... participar na defesa dos direitos das pessoas com experiência de doença mental.	4	3	2	1
38 ... ter sentido de responsabilidade.	4	3	2	1
39 ... confeccionar as minhas refeições.	4	3	2	1
40 ... ter autoconfiança.	4	3	2	1
41 ... sentir-me emocionalmente equilibrado/a.	4	3	2	1
42 ... melhorar o relacionamento com a minha família.	4	3	2	1
43 ... ser membro dos corpos sociais da organização.	4	3	2	1
44 ... ser assíduo/a.	4	3	2	1
45 ... ter consciência da minha condição física.	4	3	2	1
46 ... estar relaxado/a.	4	3	2	1
47 ... ter esperança de viver bem.	4	3	2	1
48 ... ter auto-estima.	4	3	2	1

**Annex XII – Italian Quantitative Protocol and the ACQ-CMH-48-IT**





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CIÊNCIAS PSICOLÓGICAS, SOCIAIS E DA VIDA

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## **LA SALUTE MENTALE NELLA COMUNITA'**

**MILANO, MAGGIO 2018**

## NOTE PER LA COMPILAZIONE

Le chiediamo cortesemente, prima di cominciare a compilare il questionario, di leggere alcune semplici indicazioni e di rispettarle nel corso della compilazione.

- Il questionario si compone per la maggior parte di domande a scelta multipla. Potrà fornirci le sue risposte **facendo una crocetta** sul valore della scala che meglio rappresenta il Suo pensiero.
- In caso di errore, potrà cambiare la risposta scrivendo **NO** accanto a quella sbagliata e segnando il valore che vuole scegliere.
- **È importante che Lei risponda a tutte le domande che Le vengono poste.** Ricordi che non ci sono risposte giuste o sbagliate perché ognuno ha un proprio modo di vedere le cose: **la risposta migliore è la più spontanea.**
- Il questionario è strettamente **confidenziale e anonimo**: può quindi indicarci con franchezza quello che pensa e che realmente fa. I dati saranno utilizzati al solo scopo di ricerca e in nessun modo sarà possibile risalire alla persona che ci ha fornito le risposte.



**Pensi al servizio a cui si sta rivolgendo in questo periodo. Attraverso la partecipazione alle attività dei servizi di \_\_\_\_\_ è riuscito/a...**

	<b>Per nulla</b>	<b>Poco</b>	<b>Abbastanza</b>	<b>Molto</b>
1.1. ... ad avere speranza per il mio futuro.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.2. ... a essere socievole.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.3. ... a partecipare a eventi pubblici nell'area della salute mentale (es. convegni/conferenze).	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.4. ... ad avere conoscenza di una sana alimentazione.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.5. ... a gestire i miei soldi.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.6. ... a partecipare agli eventi della vita familiare.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.7. ...a sperare di vivere una lunga vita.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.8. ... a sentirmi rispettato/a dai membri della comunità.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.9. ... ad avere la possibilità di fare attività di volontariato.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.10. ... a organizzarmi nelle attività domestiche.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.11. ... a essere autonomo/a riguardo i servizi di salute mentale.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.12. ... a sentirmi accettato/a dalla mia famiglia.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.13. ... a valorizzare le mie capacità.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.14. ... a sentirmi integrato/a nella comunità.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.15. ... a essere membro di organizzazioni.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.16. ... ad avere il controllo delle attività quotidiane.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.17. ... a essere autonomo nella gestione dei miei trattamenti medici.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.18. ... a migliorare le relazioni con la mia famiglia.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.19. ... a essere felice.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.20. ... a sentirmi a mio agio negli spazi pubblici.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.21. ... a inserire il servizio _____ nel sistema delle cure della salute mentale.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.22. ... ad avere cura della mia salute fisica (es. andare regolarmente dal medico, fare esami di routine).	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.23. ... a essere economicamente autonomo/a.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.24. ... a essere ottimista.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.25. ... ad avere un senso di appartenenza alla comunità.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.26. ... a partecipare a gruppi di auto aiuto (con altre persone con esperienza di malattia mentale, senza la presenza di professionisti).	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.27. ... ad avere senso di responsabilità.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.28. ... a essere indipendente dalla mia famiglia.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.29. ... a pensare a cose utili per la mia vita.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.30. ... a godere dell'ambiente naturale.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.31. ... a parlare di salute mentale in eventi pubblici (es. convegni/conferenze).	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.32. ... a prepararmi i pasti.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1.33. ... a prendere decisioni sulla mia vita.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>

1.34. ... ad apprezzare di più la vita.	1	2	3	4
1.35. ... ad avere nuove relazioni sociali.	1	2	3	4
1.36. ... a difendere i diritti delle persone con esperienza di malattia mentale.	1	2	3	4
1.37. ... a partecipare agli appuntamenti regolarmente.	1	2	3	4
1.38. ... a vivere in un'abitazione indipendente.	1	2	3	4
1.39. ... ad avere la possibilità di divertirmi.	1	2	3	4
1.40. ... ad interagire con i membri della comunità.	1	2	3	4
1.41. ... a essere membro di organizzazioni sociali legati alla salute mentale.	1	2	3	4
1.42. ... a essere consapevole della mia condizione fisica.	1	2	3	4
1.43. ... ad avere fiducia in me stesso.	1	2	3	4
1.44. ... a essere disposto ad accettare l'opinione degli altri.	1	2	3	4
1.45. ... a sentirmi emotivamente stabile.	1	2	3	4
1.46. ... a essere rilassato/a.	1	2	3	4
1.47. ... a sperare di vivere bene.	1	2	3	4
1.48. ... ad avere una buona autostima.	1	2	3	4

**Troverà ora alcune affermazioni che descrivono come a volte le persone si sentono rispetto a se stessi e alla propria vita.**

**Per favore legga con attenzione ogni frase e indichi la risposta che descrive al meglio il grado in cui Lei è d'accordo o meno con quell'affermazione. Indichi per ogni frase se Lei è:**

**Completamente in disaccordo (1), in disaccordo (2), non è sicuro (3), d'accordo (4), o è completamente d'accordo (5).**

	Completamente in disaccordo	In disaccordo	Non è sicuro	D'accordo	Completamente d'accordo
2.1. Ho il desiderio di farcela	1	2	3	4	5
2.2. Ho un mio progetto su come arrivare o continuare a star bene	1	2	3	4	5
2.3. Ho degli obiettivi nella vita che voglio raggiungere	1	2	3	4	5
2.4. Credo di poter raggiungere i miei attuali obiettivi	1	2	3	4	5
2.5. Ho uno scopo di vita.	1	2	3	4	5

	<b>Completamente in disaccordo</b>	<b>In disaccordo</b>	<b>Non è sicuro</b>	<b>D'accordo</b>	<b>Completamente d'accordo</b>
2.6. Anche se non m'importa di me stesso, so che altre persone si interessano a me.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.7. Capisco come controllare i sintomi della mia malattia mentale.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.8. Se mi ammalo di nuovo sono in grado di gestire la situazione.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.9. Sono in grado di identificare i fattori scatenanti i sintomi della mia malattia mentale.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.10. Sono in grado di aiutare me stesso a stare meglio.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.11. La paura non m'impedisce di vivere nella maniera che voglio io.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.12. So che ci sono dei servizi di salute mentale che mi aiutano.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.13. Ci sono cose che io posso fare per affrontare i sintomi non voluti.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.14. Sono in grado di gestire ciò che succede nella mia vita.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.15. Mi piaccio	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.16. Se le persone mi conoscessero veramente, io piacerei loro.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2.17. Sono una persona migliore ora rispetto a prima della mia esperienza di malattia mentale.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

	Completamente in disaccordo	In disaccordo	Non è sicuro	D'accordo	Completamente d'accordo
2.18. Anche se i miei sintomi possono peggiorare, so di poterli gestire.	1	2	3	4	5
2.19. Se continuo a impegnarmi, continuerò a star meglio.	1	2	3	4	5
2.20. Io ho idea di chi voglio diventare.	1	2	3	4	5
2.21. Le cose accadono per una ragione precisa.	1	2	3	4	5
2.22. Alla fine succederà qualcosa di buono.	1	2	3	4	5
2.23. Io sono la persona maggiormente responsabile	1	2	3	4	5
del mio miglioramento.					
2.24. Ho speranze per il mio futuro.	1	2	3	4	5
2.25. Continuo ad avere nuovi interessi.	1	2	3	4	5
2.26. Divertirsi è importante.	1	2	3	4	5
2.27. Affrontare la mia malattia mentale non è più il mio principale obiettivo di vita.	1	2	3	4	5
2.28. I miei sintomi interferiscono sempre meno con la mia vita.	1	2	3	4	5
2.29. Ogni volta che si ripresentano, i miei sintomi sembrano essere un problema per periodi sempre più brevi.	1	2	3	4	5
2.30. So quando è il momento di chiedere aiuto.	1	2	3	4	5
2.31. Sono disposto/a a chiedere aiuto.	1	2	3	4	5

	Completamente in disaccordo	In disaccordo	Non è sicuro	D'accordo	Completamente d'accordo
2.32. Chiedo aiuto quando ne ho bisogno.	1	2	3	4	5
2.33. Per me è importante essere in grado di lavorare.	1	2	3	4	5
2.34. So cosa mi aiuta a stare meglio.	1	2	3	4	5
2.35. Posso imparare dai miei errori.	1	2	3	4	5
2.36. Sono in grado di gestire lo stress.	1	2	3	4	5
2.37. Ho delle persone su cui posso contare.	1	2	3	4	5
2.38. Sono in grado di identificare i segni precoci di ricaduta della mia malattia.	1	2	3	4	5
2.39. Anche se non credo in me stesso, altre persone invece sì.	1	2	3	4	5
2.40. È importante avere amici di diverso tipo.	1	2	3	4	5
2.41. È importante avere abitudini di vita sane.	1	2	3	4	5

Le chiediamo ora di pensare alla qualità della Sua vita e della Sua salute . Per favore risponda a tutte le domande: se è incerto sulla risposta da fornire ad una domanda, scelga quella che corrisponde di più alla sua opinione; spesso si tratterà della risposta che Le è venuta in mente per prima. Nel rispondere tenga conto delle Sue abitudini di vita, delle Sue speranze, dei Suoi gusti e delle Sue preoccupazioni e pensi a quello che Le è successo NEGLI ULTIMI 15 GIORNI. Legga attentamente ogni domanda, rifletta sui Suoi stati d'animo e, come le abbiamo già suggerito, faccia un segno sulla risposta che meglio corrisponde alla sua opinione o ai suoi sentimenti.

3.1.	Molto cattiva	Cattiva	Né cattiva, né buona	Buona	Molto buona
Come valuta la qualità della Sua vita?	1	2	3	4	5

3.2.	Molto insoddisfatto/a	Insoddisfatto/ a	Né soddisfatto/a, né insoddisfatto/a	Soddisfatto/ a	Molto soddisfatto/a
È soddisfatto/a della Sua salute?	1	2	3	4	5

**Nelle domande seguenti Le viene chiesto in che misura Lei ha sperimentato determinate cose NEGLI ULTIMI 15 GIORNI.**

	Per niente	Poco	Abbastanza	Molto	Moltissimo
<b>3.3.</b> In che misura i dolori fisici Le impediscono di fare le cose che deve fare?	1	2	3	4	5
<b>3.4.</b> Ha bisogno di trattamenti o interventi medici per poter affrontare la vita di tutti i giorni?	1	2	3	4	5
<b>3.5.</b> Quanto si gode la vita?	1	2	3	4	5
<b>3.6.</b> In che misura Lei pensa che la sua vita abbia un significato?	1	2	3	4	5
<b>3.7.</b> Riesce a concentrarsi nelle cose che fa?	1	2	3	4	5
<b>3.8.</b> Quanto si sente al sicuro nella Sua vita di tutti i giorni?	1	2	3	4	5
<b>3.9.</b> L'ambiente in cui vive è sicuro per la salute?	1	2	3	4	5
<b>3.10.</b> Ha l'energia necessaria da poter svolgere le attività di tutti i giorni?	1	2	3	4	5
<b>3.11.</b> Accetta di buon grado il Suo aspetto esteriore?	1	2	3	4	5
<b>3.12.</b> Le Sue risorse economiche Le bastano per soddisfare i Suoi bisogni?	1	2	3	4	5
<b>3.13.</b> Le informazioni di cui dispone Le bastano per la vita di tutti i giorni?	1	2	3	4	5
<b>3.14.</b> Ha la possibilità di dedicarsi ad attività di svago nel tempo libero?	1	2	3	4	5
<b>3.15.</b> In che misura riesce a muoversi?	1	2	3	4	5

**Nelle domande seguenti, Le viene chiesto quanto si è sentito bene o soddisfatto relativamente a vari aspetti della Sua vita negli ULTIMI 15 GIORNI.**

	Molto insoddisfatto /a	Insoddisfatto /a	Né soddisfatto/a, né insoddisfatto/a	Soddisfatto /a	Molto soddisfatto /a
<b>3.16.</b> È soddisfatto/a di come dorme?	1	2	3	4	5
<b>3.17.</b> È soddisfatto/a di come riesce a fare le cose di tutti i giorni?	1	2	3	4	5

	<b>Molto insoddisfatto /a</b>	<b>Insoddisfatto /a</b>	<b>Né soddisfatto/a, né insoddisfatto/a</b>	<b>Soddisfatto /a</b>	<b>Molto soddisfatto /a</b>
<b>3.18.</b> È soddisfatto/a della Sua capacità di impegnarsi in attività?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3.19.</b> È soddisfatto/a di Se stesso?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3.20.</b> È soddisfatto/a dei Suoi rapporti personali con ali altri?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3.21.</b> È soddisfatto/a della Sua vita sessuale?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3.22.</b> È soddisfatto/a del sostegno che riceve dai Suoi amici?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3.23.</b> È soddisfatto/a delle condizioni della Sua abitazione	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3.24.</b> È soddisfatto/a della disponibilità ed accessibilità dei servizi sanitari?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3.25.</b> È soddisfatto/a dei mezzi di trasporto che ha a disposizione?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

<b>3.26.</b>	<b>Mai</b>	<b>Raramente</b>	<b>Abbastanza spesso</b>	<b>Molto spesso</b>	<b>Sempre</b>
Quanto spesso prova dei sentimenti negativi, come cattivo umore, disperazione, ansia o depressione?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

Con le seguenti domande desideriamo sapere come Lei si è sentito/a nel corso degli ultimi 30 giorni. Per ogni domanda le preghiamo di fare un segno sul numero che indica quanto spesso si è sentito/a in questo modo.

4.1. Nel corso degli ultimi 30 giorni, con che frequenza si è sentito/a...	Mai	Raramente	A volte	Spesso	Sempre
4.1.1. ... nervoso/a?	1	2	3	4	5
4.1.2. ... senza speranza?	1	2	3	4	5
4.1.3. ... irrequieto/a o ha avuto difficoltà a tenere ferme braccia e gambe (una specie di irrequietezza)?	1	2	3	4	5
4.1.4. ... così depresso che niente riusciva a tirarla su?	1	2	3	4	5
4.1.5. ... come se ogni cosa rappresentasse uno sforzo?	1	2	3	4	5
4.1.6. ... inutile?	1	2	3	4	5

4.2. Le domande precedenti servivano a raccogliere informazioni su come si è sentito negli ultimi 30 giorni. Complessivamente si è sentito in questo modo meno spesso, come o più spesso del solito? (Se non si è mai sentito/a così, faccia comunque un cerchio sulla risposta "4" - "Come al solito").

Molto meno spesso del solito	Meno spesso del solito	Un po' meno spesso del solito	Come al solito	Un po' più spesso del solito	Più spesso del solito	Molto più spesso del solito
1	2	3	4	5	6	7

Le domande che seguono, infine, riguardano il modo in cui questi stati d'animo (nervosismo, tristezza, mancanza di speranza, stanchezza, ecc.) possono averla influenzata negli ultimi 30 giorni. Non è necessario che lei risponda se ha risposto "Mai" a tutte le sei domande precedenti.

4.3. Quanti giorni, negli ultimi 30, è stato completamente incapace di lavorare o portare a termine le normali attività quotidiane per come si è sentito/a?

\_\_\_\_\_ (Numero di giorni)



**4.4. Senza contare quelli che ha indicato nella risposta precedente, per quanti giorni, negli ultimi 30, è stato/a in grado di fare solo metà o meno del normale per come si è sentito/a?**

\_\_\_\_\_ (Numero di giorni)

**4.5. Negli ultimi 30 giorni quante volte si è rivolto/a ad un medico o un altro operatore sanitario per come si è sentito/a?**

\_\_\_\_\_ (Numero di volte)

<b>4.6.</b>	<b>Mai</b>	<b>Raramente</b>	<b>A volte</b>	<b>Spesso</b>	<b>Sempre</b>
Negli ultimi 30 giorni quanto spesso questi stati d'animo sono stati causati principalmente da problemi di salute fisica?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

<b>Dati dell'intervistato</b>
1. Età ____ anni
2. Data di nascita ____/____/____
3. Genere <input type="checkbox"/> Maschio <input type="checkbox"/> Femmina
4. Nazionalità _____
5. Stato civile <input type="checkbox"/> Celibe/nubile <input type="checkbox"/> Separato/a <input type="checkbox"/> Divorziato <input type="checkbox"/> Vedovo/a <input type="checkbox"/> Sposato/a <input type="checkbox"/> Altro (specificare) _____
6. Ha figli? <input type="checkbox"/> No <input type="checkbox"/> Si Se ha risposto "Si", può indicare quanti? _____
<b>Abitazione</b>
7. Qual è la sua situazione abitativa? <input type="checkbox"/> Vivo in una residenza comunitaria <input type="checkbox"/> Vivo in un'abitazione indipendente. <input type="checkbox"/> Specificare la tipologia di abitazione _____
<input type="checkbox"/> Vivo con familiari. <input type="checkbox"/> Specificare con chi vive _____
<input type="checkbox"/> Altro. Specificare _____

8. Ha scelto lei la sua attuale soluzione abitativa?  Sì  No

9. Desidererebbe vivere da un'altra parte?  Sì  No  
 Se ha risposto "Sì", specifichi dove \_\_\_\_\_

10. Si è mai trovato senza una fissa dimora?  Sì  No  
 Se ha risposto "Sì":

- Può indicare quanto tempo è durata questa situazione? \_\_\_\_\_
- Il servizio di cui usufruisce l'ha aiutata a uscire da questa situazione?  Sì  No

**Istruzione**

11. Qual è il suo grado di istruzione? (può barrare più di una casella)

- Non so leggere né scrivere
- So leggere e/o scrivere
- Scuola elementare
- Scuola media
- Scuola superiore
- Qualifica professionale (ad esempio competenze di ufficio, cameriere, segretario, ecc.)
- Laurea triennale
- Laurea specialistica
- Master o dottorato
- Altro  
(specificare) \_\_\_\_\_

12. Attualmente è uno studente?  Sì  No

Se ha risposto "No", può dirci a quando risale la sua ultima esperienza scolastica?  
 \_\_\_\_\_

Se ha risposto "Sì":

- specifichi il tipo di scuola, quale corso sta svolgendo e se si tratta di un tipo di formazione rivolta a membri della comunità in generale o solo a persone con problemi nell'ambito della salute mentale  
 \_\_\_\_\_
- La sua attuale esperienza di studio è merito del servizio?  Sì  No
- E' stata una sua scelta quella di studiare?  Sì  No

13. Desidera realizzare altre esperienze di studio?  Sì  No  
 Se ha risposto "Sì", può specificare cosa desidererebbe fare?  
 \_\_\_\_\_

**Formazione professionale**

14. Attualmente frequenta un corso di formazione professionale?  Sì  No  
 Se ha risposto "Sì", può specificare di cosa si tratta? (quale corso sta svolgendo e se si tratta di un tipo di formazione rivolta a membri della comunità in generale o solo a persone con problemi nell'ambito della salute mentale)  
 \_\_\_\_\_

## Lavoro

15. Qual è la sua situazione lavorativa?

- Dipendente
  - Volontario
  - Apprendista
  - Disoccupato
  - Altro (specificare)
- 
- 

16. Se attualmente **non svolge** attività lavorative:  
Quale e quanto tempo fa è stata la sua ultima esperienza?

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17. Se attualmente **svolge** attività lavorative:

- Può specificare di cosa si tratta? (Tipo di impresa, quale funzione svolge, se si tratta di un tipo di lavoro rivolto a membri della comunità in generale o solo a persone con problemi nell'ambito della salute mentale)
- 
- 

- Ha ottenuto questo lavoro grazie al servizio?  Sì  No
- Ha scelto lei di realizzare questa attività professionale?  Sì  No

18. Desidera realizzare altre attività professionali?  Sì  No  
Se ha risposto "Sì", può specificare quale/i?

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## Salute mentale

19. Siete a conoscenza della vostra diagnosi di salute mentale?  Sì  No  
Se sì, potreste indicare qual è?

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20. Di quale servizio di salute mentale usufruisce attualmente?

- Consulenza esterna (psichiatrica o psicologica)
  - Ospedale
  - Centro diurno
  - Cure farmacologiche
  - Servizi domiciliari
  - Residenza comunitaria
  - Altro (Specificare)
- 
- 

21. E' mai stato ricoverato in ospedale per un trattamento psichiatrico?  Sì  No  
Se ha risposto "Sì", può specificare quante volte? \_\_\_\_\_

22. Da quando ha incominciato a frequentare il servizio è mai stato ricoverato in ospedale per un trattamento psichiatrico?  Sì  No  
Se ha risposto "Sì", può specificare quante volte? \_\_\_\_\_

## Partecipazione al servizio

23. Da quanto tempo frequenta il servizio? \_\_\_\_\_

24. A quali programmi/attività del servizio partecipa?

- Attività occupazionali
- Attività culturali
- Formazione su competenze di vita
- Psicoterapia di gruppo
- Gruppi di auto-mutuo aiuto
  
- Attività sportive di gruppo
- Attività sportive individuali
  
- Residenza comunitaria
- Servizi domiciliari
  
- Supporto individuale attraverso un piano personalizzato di recovery
- Supporto individuale attraverso un piano terapeutico
  
- Corsi scolastici organizzati all'interno del servizio
- Corsi scolastici esterni al servizio rivolti a persone con problemi di salute mentale
- Corsi scolastici esterni al servizio rivolti a tutta la comunità
  
- Corsi di formazione professionale organizzati all'interno del servizio
- Corsi di formazione professionale esterni al servizio rivolti a persone con problemi di salute mentale
- Corsi di formazione professionale esterni al servizio rivolti a tutta la comunità
  
- Inserimento professionale con altre persone con problemi di salute mentale
- Inserimento professionale con altre persone di tutta la comunità
  
- Altro (specificare)

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## Caratteristiche generali

A. Nome dell'organizzazione

B. Codice identificativo dell'organizzazione

C. Nome dell'intervistatore

D. Data dell'intervista \_\_\_\_ / \_\_\_\_ / \_\_\_\_

E. Codice identificativo del partecipante \_\_\_\_\_

**GRAZIE PER LA COLLABORAZIONE**