A transformation strategy for Protective Workshops: Towards comprehensive services for adults with intellectual disability

by

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DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment is my original work and that I have not previously submitted it, in its entirety or in part, to any university for a degree.

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ABSTRACT

South African Protective Workshops struggle to transform to align to a developmental human rights approach and to increase sustainability in the absence of a uniform model and an implementation strategy.

This study applied qualitative research methodology in the form of Action Research with Co-operative Inquiry to answer the research question of what could be a framework of best practice for and strategy of transformation for protective workshops (PWs) operated by the South African Federation for Mental Health (SAFMH) in South Africa.

It included the development of a transformation strategy for 31 PWs for adults with intellectual disability operated by SAFMH member organisations across South Africa. Seven representatives from the managers and service users of PWs were selected trough convenient sampling. The participants formed a co-operative inquiry group to determine the nature of the service to be delivered and how it should be implemented. The purpose was to develop a framework for possible and relevant services for persons with intellectual disability. Such services should preferably be aligned to the human rights based legislation and funding requirements of the Department of Social Development as to increase the long-term sustainability of the PWs.

Given that the study was funded by the SAFMH, the directors requested that the Co-operative Inquiry Group use the exisisting best practice model used by Cape Mental Health as a template and point of departure. The study was done over a 12-month period (February 2012 – February 2013) and included a research initiation meeting, four search conferences and a presentation of the findings to the SAFMH Directors.

The study contributed new knowledge on the nature of service provision to persons with ID and the ideal process to transform services within the SAFMH context. Through inductive content analysis two themes emerged namely: 1) Comprehensive service provision and 2) Coordinated transformation of services.

The first theme determined that comprehensive services to persons with ID should consist of inclusive, appropriate, enabling and empowering services. The second theme suggested a new way of coordinating the transformation of services through systematic implementation, suitable regulation, sufficient capacity and ensuring sustainability. A central management structure was suggested to ensure coordinated implementation, to secure funding and to monitor and evaluate the implementation.

A mind-shift towards new thinking was identified as a prerequisite for stakeholders buy-in on transformed service delivery. This mind-shift relates to the status of the service users with ID as adults in training towards employment in the open labour market and maximum integration into society.

This study contributed new knowledge that informs the development of a new service delivery framework of best practice. The proposed implementation strategy could offer persons with ID the opportunity to progress and develop towards their maximal level of integration into society. It further provided PWs with possibilities for conceptualising different models of practice in the form of an implementable framework and a strategy to transform services. The findings were presented to the SAFMH Directors who adopted the concept framework and implementation strategy in theory as a proposal for future transformation without amendments.

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OPSOMMING

Suid-Afrikaanse Beskermde Werkswinkels vind dit moeilik om te transformeer na 'n ontwikkelingsbenadering wat op menseregte gegrond is en om hul volhoubaarheid te verbeter in die afwesigheid van 'n eenvorminge model en 'n strategie vir implimentering.

Hierdie studie het kwalitatiewe navorsingsmetodes in die vorm van Aksie Navorsing met Koöperatiewe Ondersoeke gebruik om ’n transformasie strategie vir die 31 Beskermde Werkswinkels vir volwassenes met intellektuele gestremdheid, wat bestuur word deur die lidorganisasies van die South African Federation for Mental Health (SAFMH) regoor Suid-Afrika. Die koöperatiewe ondersoekspan het bestaan uit verteenwoordigers van die werkswinkel bestuurders en gebruikers van die dienste wat geselekteer is deur middel van gerieflikheidsteekproefneming. Hulle ondervinding het meegewerk om vas te stel wat die aard van die dienste moet wees en hoe dit effektief geïmplementeer kon word. Die doel van die studie was om dienste daar te stel vir persone met intellektuele gestremdheid wat in lyn is met menseregte wetgewing en die riglyne vir befondsing deur die Departement van Maatskaplike Dienste om sodoende die langtermyn volhoubaarheid van die werkswinkels te verbeter.

Omdat die studie deur SAFMH befonds is, het die direkteur die koöperatiewe ondersoekspan gevra om die Cape Mental Health model as ’n beginpunt te gebruik aangesien dit reeds as ’n beste praktyk model in die sektor erken word. Die studie is oor ’n periode van 12 maande uitgevoer (Februarie 2012 – Februarie 2013). Dit het ’n inisiasie vergadering, 4 ondersoek konferensies en ’n aanbieding van die bevindinge aan die SAFMH-direkteure ingesluit.

Die eerste tema het nuwe insig gegee oor die aard van dienste aan persone met intellektuele gestremdheid en die ideale manier om dit te implementeer om te transformeer van huidige na beste praktyk status binne die SAFMH konteks. Deur induktiewe inhoud analise het twee temas na vore gekom vanuit die kodes, sub-kategorieë en kategorieë. Die eerste tema het gedui op omvattende dienste aan persone met intellektuele gestremdheid in die vorm van inklusiewe dienste, toepaslike dienste, dienste wat persone in staat stel en dienste wat hulle bemagtig.

Die tweede tema het nuwe kennis opgelewer aangaande die gekoördineerde transformasie van dienste deur sistematiese implementering, toepaslike regulering, genoegsame kapasiteit en deur te verseker dat dit volhoubaar is op die lang duur. ’n Sentrale bestuursentrum is voorgestel om gekoördineerde implementering te verseker. ’n Nuwe denkwyse oor die status van volwassenes met intellektuele gestremdheid deur alle belanghebbendes is geïdentifiseer as ’n voorvereiste vir die aanvaarding en suksesvolle implementering van die transformasie strategie. Hierdie persone moet gesien word as volwassenes wat in opleiding is om in die ope arbeidsmark te werk en op die hoogste vlak van integrasie in hulle gemeenskappe te funksioneer.

Die nuwe kennis het gelei tot die ontwikkeling van ’n nuwe diensleweringsraamwerk en implementeringstrategie wat persone met intellektuele gestremdheid die geleentheid kan gee om maksimaal te ontwikkel en te integreer in hulle gemeenskappe. Dit bied verder aan beskermde werkswinkels die geleentheid om alternatiewe modelle van dienslewering te oorweeg. Die bevindinge is aan die SAFMH-direkteure voorgelê en die raamwerk en strategie vir implementering is in teorie aanvaar sonder enige veranderinge.

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It is with great appreciation that I acknowledge the following organisations and persons for their contribution to this study and this thesis:

- The South African Federation for Mental Health (SAFMH) for the vision to realise the need for a framework of best practice and implementation strategy to provide guidance to the protective workshops in the process of transformation. Further for the trust they showed in the Protective Workshop Unit members to undertake the study and the funding of the study.
- The mental health societies for allowing the managers and service users to be part of the study and for arranging cover for their duties during the times they attended meetings and search conferences as part of the study.
- The protective workshop managers and service user representatives on the co-operative inquiry group for your commitment, dedication and perseverance throughout the study. It was a privilege to work alongside you. I admire your passion, compassion and dedication for and to persons with intellectual disability.
- My study leaders for the guidance and assistance throughout the study.

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DEDICATION

This thesis is dedicated to all persons with intellectual disability in South Africa. I trust that the outcome of this study and the transformation of protective workshops would assist you in your development and progression towards full integration into society to take up your rightful place as equal South African citizens.

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LIST OF ACRONYMS

AAIDD: American Assosiation on Intellectual and Developmental Disabilities[1]

AR: Action Research[2]

BBBEE: Broad Based Black Economic Empowerment[3]

CBR: Community Based Rehabilitation[4]

CIG: Cooperative Inquiry Group

CMH: Cape Mental Health[5]

CSI: Corporate Social Investment

DPO: Disabled Persons' Organisation

DSD: Department of Social Development[6]

HWSETA: Health and Welfare Sectorial Education and Training Authority[7]

I-CAN: Instrument for the Classification and Assessment of Support Needs[8]

ID: Intellectual Disability

NGO: Non-Government Organisation

NQF: National Qualifications Framework[9]

OLM: Open Labour Market

PD: Psychiatric Disability

PW: Protective Workshop

SAFMH: South African Federation for Mental Health[10]

SAMHAM: South African Mental Health Advocacy Movement[10]

SAQA: South African Qualifications Authority[9]

SE: Supported Employment[11]

SIS: Supports Intensity Scales[12]

TWU: Training Workshops Unlimited[5]

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities[13]

VdTMoCA: Vona du Toit Model of Creative Ability[14]

WHO: World Health Organisation[4]

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DEFINITIONS

Action Research (AR): A research method that consists of cycles of planning, action, observation, reflection and re-planning in an attempt to solve real situational problems in service delivery and practice by the persons in the situation working together to find solutions to the problems.[2]

Best Practice Model: "A method or technique that has consistently shown results superior to those achieved with other means, and that is used as a benchmark."[15]

Co-operative Inquiry Group (CIG): A research tool that involves two or more people using their own experience of a topic in researching it while moving through cycles of being part of the experience and reflecting on the experience.[16]

Integrated environment refers to a setting that enables persons with disabilities to participate amongst and with persons from mainstream society.

Intellectual Disability (ID): A chronic developmental disorder that involves impairments of general mental abilities that impact adaptive functioning in the domains of conceptual, social and practical functioning with an onset during the developmental period.[17]

Maximal integration refers to the highest level of integration achievable whithin the limitations presented by the nature of the disability and the available support and resources.

National Qualifications Framework (NQF): A framework consisting of 10 levels to provide a vision, philosophical base and an organisational structure in which all education and training in South Africa fits.[9]

Open Labour Market refers to a labour market where employees (including persons with disabilities) compete on an equal basis for competitive paid employment[18]

Protective Workshop (PW): A facility that provides a day programme including rehabilitation services and "work" opportunities to persons with disabilities who experience barriers in accessing employment in the open labour market.[19]

Reasonable accommodation: Modifications, alterations or support provided by the employer in the workplace to enable a suitably qualified person with a disability to perform the job as everybody else.[20]

Search Conference (SC): A meeting of relevant stakeholders under island conditions (away from everyday responsibilities) for 2-5 days to construct a picture for a desirable future for organisational settings.[21]

Self-advocacy: "learning how to speak for yourself, making your own decisions about your own life, learning how to get information so that you can understand things that are of interest to you, finding out who will support you in your journey, knowing your rights and responsibilities, problem solving, listening and learning, reaching out to others when you need help an friendship, and learning about self-determination."[22]

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Self-advocate(s) supporter: A person supporting self-advocates[22]

Service users: Adults with ID registered at PWs

South African Department of Social Development (DSD): A national South African government department responsible for ensuring developmental social welfare services, social security, social assistance and poverty alleviation programmes in partnership with implementing agents including non-governmental organisations (NGOs).[6]

South African Federation for Mental Health (SAFMH): The SA Federation for Mental Health is a registered national, not-for-profit, non-governmental organisation (000-238 NPO) that aims to co-ordinate, monitor and promote services for persons with intellectual disability and persons with psychiatric disability (mental illness) as well as promoting mental health and well-being. It is the umbrella body for 17 mental health societies and numerous member organisations throughout the country. The societies and members are accountable to the Federation so far as the standard of service delivery is concerned.[10]

South African Federation for Mental Health Protective Workshops (SAFMH PWs): Protective workshops operated by mental health societies or member organisations affiliated to the South African Federation for Mental Health and providing services to clients with intellectual and/or psychiatric disability.[10]

South African Mental Health Advocacy Movement (SAMHAM): A national self-advocacy group of service users of mental health societies affiliated to the South African Federation for Mental Health.[10]

South African Qualifications Authority (SAQA): An official body responsible for the verification of South African qualifications achievements, the keeping of a national learner database, the registration of all South African qualifications and the evaluation of foreign qualifications.[9]

Support for persons with ID is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD)[1,12] as resources and strategies necessary to promote the development, education, interests and well-being of a person with intellectual disability and can be provided by family, friends, community members, professionals or agencies.

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Chapter 1 INTRODUCTION

1.1 Introduction

Although the transformation of South African protective workshops (PWs) has been a priority since 1994, it still was not achieved at most PWs[23]. The lack of transformation by the protective workshops (PWs) operated by the members of the South African Federation for Mental Health was identified as the problem statement for this study. The researcher argues that the lack of transformation in most SAFMH PWs is due to a lack of understanding by management and staff of the expectations for transformation set by the Department of Social Development (DSD). In the opinion of the researcher, most SAFMH PWs are still providing a service that is aimed at "protecting" the service users with ID from the dangers and stigma of the world by accommodating them in a safe space separate from mainstream society. The expectation that transformation should provide services based on the human rights of persons with ID at maximal level of integration falls outside of their current frame of reference. A contributing factor is the non-exposure of the managers and staff to best practice programmes that could enlighten them to what is possible.

The researcher further believes that the absence of a best practice model and implementation strategy to guide transformation is a contributing factor to the lack of transformation in the PW sector.

This study therefore focused on the transformation of the services provided by the South African Federation for Mental Health (SAFMH)[10] protective workshops (PWs) for them to be relevant and contributing role players in the development and empowerment of adults with intellectual disability (ID) in South Africa.

The SAFMH[10] is a national non-profit mental health organisation consisting, inter alia, of 17 mental health societies as members located across all nine provinces of South Africa and the national office in Randburg, Gauteng. The 17 member societies are all independent non-profit organisations offering mental health services in their designated operational areas. Each member society has its own Board and Executive Committee. Some SAFMH PWs only accommodate persons with intellectual disability and others offer placement for both persons with intellectual and psychiatric disabilities. For the purpose of this study, the focus is on services for persons with intellectual disability.

The SAFMH, as a separately registered non-profit organisation, does not have line management authority or decision-making powers in the operations of any of the 17 member organisations. The SAFMH does not provide direct services to any service users with mental disabilities. The role of SAFMH[10] is to work with and support the work of its member organisations. This support includes liaison with national government departments and other key stakeholders relating to the mental health sector, exploring

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and developing best practice programmes that member organisations could consider for implementation as well as public education and raising awareness relating to mental health disorders, prevention and promotion.

The SAFMH itself therefore does not operate any PWs, but most of the member organisations operate one or more PWs for persons with mental disabilities in their respective operational areas. This structure results in a total of 31 SAFMH PWs (refer to Appendix A).

The outcome of a workshop, held in February 2011 and attended by the SAFMH Directors and PW managers of the 17 mental health societies, concluded that the lack of transformation of most SAFMH PWs was due to the absence of a uniform model of service provision and a lack of a structured transformation strategy to assist PWs in the process. As an outcome of that workshop a Protective Workshop Unit (SAFMH PW Unit) was mandated by the SAFMH Board and reported directly to the SAFMH Executive Director. The researcher was a member of this PW UnitThe purpose of the SAFMH PW Unit was to guide the transformation process on behalf of the SAFMH PWs. The proposed transformation was also a strategy to align it to the DSD Policy on PWs to ensure continued subsidies to increase sustainability. The SAFMH PW Unit was present at the Research Initiation Meeting in February 2012 and was responsible for drafting the initial study plan and budget for submission to and approval by the SAFMH Directors for this study.

As part of the empowerment of self-advocates in the mental health sector, SAFMH initiated and provided support to the South African Mental Health Advocacy Movement (SAMHAM)[10], a mental health service user advocacy body consisting of mental health service user representatives from member mental health societies. The SAMHAM is supported by a SAFMH staff member. Its activities include a quarterly newsletter, teleconferences, workshops and attending various forums and summits to represent persons with mental disabilities. The SAFMH includes service users in decision making about service delivery and therefore has two seats on the SAFMH Board reserved for service users. The SAFMH therefore also required service user participation in this study.

Besides the researcher, the co-operative inquiry group (CIG) consisted of the four other PW managers on the SAFMH PW Unit, a SAFMH staff member and two SAMHAM service users (refer to Participants on page 32) selected through convenient sampling . The other PW managers and the SAFMH staff member on the CIG had a range of different qualifications and backgrounds: two of the PW managers and the SAFMH staff member were qualified and registered social workers, one PW manager came from a business background and the other had a qualification as a project manager. The two service users came from different provinces and different PW structures and could provide input from two different perspectives.

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The researcher is a qualified and registered Occupational Therapist with 15 years' experience working in a SAFMH Protective Workshop environment at the time of this study. The role of the researcher included knowledge of disability and expertise in overcoming barriers of social inclusion as part of the transformation process of a group of 4 PWs in Cape Town. These PWs operated as a collective under the trade name of Training Workshops Unlimited (TWU) by Cape Mental Health (CMH)[5] providing day programmes to more than 500 adults with intellectual disability.

During the period between 1997 and 2005, first as the TWU Training and Development Manager and later as the TWU General Manager, the researcher was tasked by Cape Mental Health (CMH) with the transformation of the 4 CMH PWs to ensure alignment with the Department of Social Development (DSD) Policy on PWs[19]. Besides being responsible for the overall management of TWU, the researcher was involved in programme development, staff training and development, exploring post-school qualifications for persons with ID and service user advocacy initiatives. Through networking and liaison with other SAFMH PWs, the researcher noted that most of the SAFMH PWs had not undergone transformation. This meant that their service users did not have access to best practice programmes. The researcher realised that her specialised knowledge and experience of the transformation of PWs for persons with ID could assist the other SAFMH PWs to transform successfully and to strengthen the SAFMH PW movement.

When the SAFMH commissioned and funded this study, the researcher agreed to lead the study in order to ensure that persons with ID registered at these workshops would have access to best practice service provision.

The researcher and co-researchers had to work within the framework set by the SAFMH Directors for this study, including the time frame (February 2012 – March 2013), the funding allocated and the aim of the research.

The SAFMH Directors identified the model of transformation implemented by Cape Mental Health[5] (a SAFMH member Mental Health Society) at its PWs as an innovative model that could inform the development of the SAFMH model. The SAFMH Directors indicated that the CMH model could not be adopted as the SAFMH Framework, since it had only been implemented in Cape Town at that time and might not meet the needs of the service users at all the SAFMH PWs in urban, peri-urban and rural areas. The SAFMH Directors therefore instructed the CIG to use the CMH PW Model as a starting point in this study. The researcher will therefore refer to the CMH model and explain how it informed the development of the new framework of best practice developed in this study in the next section.

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1.2 Background and history of protective workshops in South Africa

South African PWs developed within the disability sector since 1977 as facilities providing day programmes to adults with severe disabilities whose functionality and productivity did not necessitate institutional care, but were too low to qualify for employment in sheltered employment factories[24]. The Department of Social Development (then called the Department of Social Welfare and Pensions) sent a circular (No. 86 of 1977)[25] to welfare organisations announcing a subsidy scheme to start and run PWs for persons with severe disabilities in the community.

According to this circular (No. 86 of 1977)[25], the aims of PWs were:

– to provide purpose and routine to the lives of people with disabilities

– to develop their sense of independence and self-esteem

– to develop their mental and physical abilities optimally through the challenges of a day programme and work activities

– to create an environment that is conducive to socialising and social adaptation

– to prevent their dependency on caregivers and becoming a care burden

– to develop their ability to work to the benefit of the South African economy

It was suggested that smaller organisations with limited resources form a partnership with other welfare organisations to start a workshop serving a “collective” of their clients.

The Draft Audit Report (2011) of the Department of Social Development (DSD) study on PWs[23] shows that:

- Most PWs exist in urban and peri-urban areas and provide services to a specific client base, as can be seen in the existence of separate workshops for persons with blindness, deafness, intellectually disability, physical disability, epilepsy, cerebral palsy and others. In more rural areas, with smaller welfare organisations with fewer resources, statistics show that PWs are more integrated and provide services to persons with different disabilities[19].
- Although the development of PWs in South Africa provided a safe haven for persons with severe disabilities at the time, it also created a parallel segregated society for persons with disabilities. The PWs provide them with simulated activities similar to real life situations i.e. work activities, sport and leisure activities and opportunities for socialisation. The work activities that the service users are involved in at PWs does not ensure sufficient income for PWs to pay market related wages for work done. Most PWs therefore pay their service users a small incentive on a weekly or monthly basis to simulate a wage to keep the service users motivated.

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- Despite the new focus on human rights in post-Apartheid South Africa since 1994, the programmes at most PWs remained the same and are not aimed at the re-integration of the service users into mainstream society and the open labour market. This results in persons with disabilities still remaining in a segregated society at most PWs for most of their adult lives without any option for integration into mainstream society. Although PWs were started to treat the symptoms of a non-inclusive society, the perception changed to where PWs are now blamed for sustaining segregation of persons with disability.

The PWs are therefore presented with the challenge to transform.

1.2.1 The transformation challenge for PWs

Following the first democratic elections in South Africa in 1994 and the new South African Constitution[26], the focus shifted to equal human rights for all. Special emphasis has been placed on corrective action for previously disadvantaged groups, including black people, women, youth and persons with disabilities as can be seen in the Broad Based Black Economic Empowerment Act (No. 53 of 2003)[3] and the Employment Equity Act (No. 55 of 1998)[20], as well as the Code of Good Practice on the Employment of People with Disabilities[27]. The new focus on equal human rights for persons with disabilities can be seen in the White Paper on the Integrated National Disability Strategy (1997)[28] and the South African Government's signing and ratification of the United Nations Declaration on the Right of Persons with Disabilities[13].

The social development policies subsequently changed to reflect this human rights approach, as can be seen in the White Paper for Social Welfare[29], the DSD Policy on Disability[30] and the DSD Policy on PWs[19]. As outlined in the Policy on PWs[19], PWs are under pressure to transform from a predominantly medical model (which focuses on inability and cure) to a Developmental Model (with a BioPsychoSocial and Interactionist approach). The aim of the developmental model is to address the medical aspects of disability whilst also correcting the environmental or systemic conditions that form barriers and prevent the integration and empowerment of persons with disabilities regardless of the degree of their disability.

In the Policy on PWs[19], DSD prescribes a developmental model for service provision in PWs consisting of a Psycho-social Services Unit, a Skills Development Unit and an Entrepreneurial Development Unit, as can be seen in Figure 1.1.

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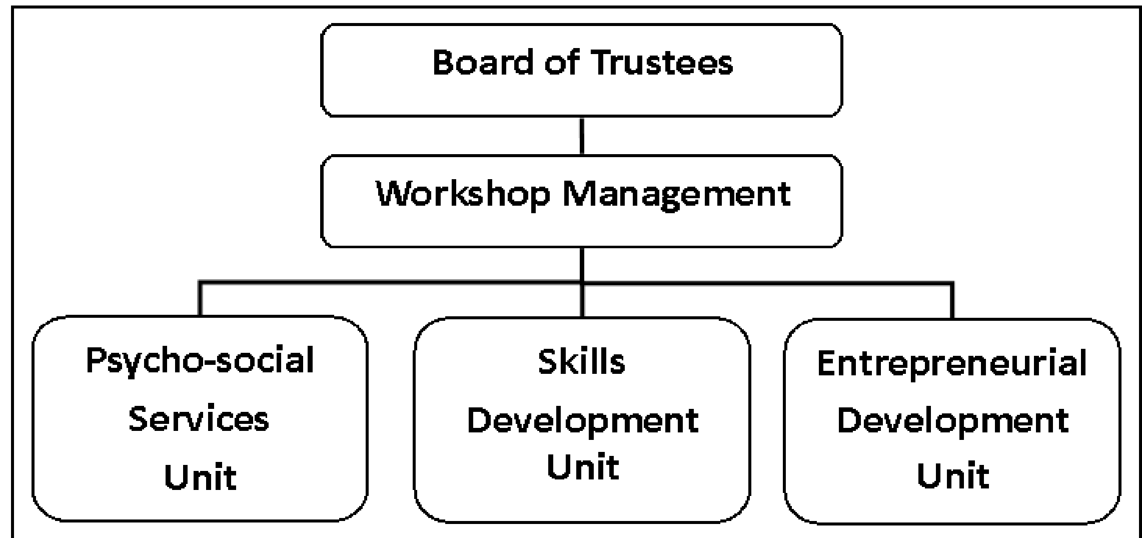

Figure 1.1 DSD Model for Protective Workshops[19]

According to the policy, PWs may choose to focus on psycho-social services only (depending on the abilities of their service users) or alternatively include the economic development services. The policy further states that the three units should work in collaboration with one another to provide a holistic and integrated service.

The policy requires PWs to transform in three critical areas, as identified during the DSD study on PWs, namely:

- Strategic Leadership and Management Structures
- Service Delivery Structures and Processes
- Operational Policies and Systems

These three areas were identified by DSD as most PWs function without formal structures and systems and are therefore unable to deliver optimal services. Financial constraints at most PWs preclude the appointment of skilled staff that exact higher salaries. This may have been the result in managers not having the necessary leadership skills or management training[23]. Although most managers have a passion for their work and their service users, they did not have the management and financial skills to run a PW successfully.

Before the publication of the Policy on PWs in 2011, DSD strongly urged PWs to transform, but no real evidence of transformation could be found during monitoring and evaluation visits conducted by DSD at most PWs[19,23]. The researcher contends that, with this DSD publication, the policy provided PWs with an outline of a model for a transformed protective workshop, but failed to provide a transformation strategy and the necessary support that would be needed for successful transformation.

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Additional criticism that the researcher levels at the Policy on PWs includes:

- The policy does not acknowledge the wide range of functional abilities and needs of persons with intellectual disability (refer to Appendix B) and does not make provision for programmes at different levels of intervention within the units to address these needs, as can be seen from the single-programme approach within the different units of the model.
- The policy refers to service users of PWs as the workforce, implying that all service users are involved in production activities; this is not the case, however, as a large percentage (54% in the case of the Cape Mental Health PWs[5]) participate in life skills, care and stimulation programmes and can thus not be regarded as workers.
- The proposed management structure and programmes do not take into account the differences in size amongst existing workshops (varying from as few as 12 to more than 200 service users per workshop) that have an impact on the number of programmes and the number of staff the workshops can sustain.
- The policy requires PWs to have their own Board of Trustees and does not acknowledge that a large number of PWs operate as projects of parent organisations (as is the case with SAFMH members) and are not separate legal entities in need of their own board of trustees.
- The policy sets the requirement for all social services to be provided by qualified and registered social workers and health promotion programmes by occupational therapists or other health professionals registered with the nursing council. In the opinion of the researcher this requirement would be ideal, but in reality would not be feasible within the limited financial resources available for staffing at PWs that are already struggling with sustainability (as confirmed by DSD in the Policy on PWs[19]). Again the minimum standard was set, but not supported in the form of funding of posts by DSD. Social workers, occupational therapists and nurses are regarded as professionals with scarce skills in the South African context (HWSETA Presentation at the Stakeholder Engagement in Cape Town on 29 May 2014[7]) and these services are not readily available in the peri-urban and rural areas (as evident in the results of the needs analysis done by Cape Mental Health in the Eden/Karoo district in the Western Cape in 2013[31]).

1.2.2 Funding for and sustainability of Protective Workshops in South Africa

Historically, the financial sustainability of South African PWs was dependent on government subsidies[19]. The DSD subsidises PWs in accordance with the Social Assistance Act[32]. The initial subsidy announced in 1977 made provision for a once-off subsidy for capital expenses related to the start-up of a workshop and an on-going subsidy for running costs[25]. In order to break even, PWs had to complement the income

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from subsidies with only limited income from business activities, donations, fundraising and (in some instances) financial aid from parent organisations.

The sustainability of PWs came under serious strain over the years with limited or no increases in subsidies (as can be seen in the Transfer Payment Agreements entered into between the DSD and PWs), the international recession which reduced outsourced business opportunities, and dwindling resources for corporate funding and donations (as reported at Cape Mental Health Society's Financial Meeting of April 2012 which was attended by the researcher).

Currently DSD subsidisation of PWs exists in the form of a per head subsidy based on attendance. This subsidy is paid by provincial DSD departments and the amount per head is different for each province ranging from no subsidy for PWs in some provinces to R 659 per service user per month in KwaZulu-Natal in 2012. In the Western Cape the subsidy remained at the same amount per head for the period 2001 to 2011 (R 181 per service user per month), while the average monthly Consumer Price Index for the same period reflected an increase of 6%[33].

From the above it is clear that the SAFMH PWs needed to transform to stay relevant and needed strategies to ensure long term sustainability if it wanted to remain a key service provider to persons with ID in South Africa.

1.3 Commissioning of the study

The results of a study by DSD on South African PWs done in 2009[23] showed that most PWs that participated in the study provided their service users with opportunities to earn small incentives by participating in low-level repetitive production activities only, with little evidence of capacity building or empowerment. This is in contrast to the model suggested by DSD[19] in that most workshops had neither programmes nor structures to promote self-advocacy, nor programmes to prepare or support their service users to access exit opportunities i.e. to secure employment in the open labour market. It can therefore be concluded that most South African PWs are not aligned with the proposed DSD Model for PWs. This DSD study mentioned above concluded that, although most workshops supported and understood the need for transformation, they did not know how to transform in the absence of a best practice model and transformation strategy.

A South African protective workshop model that does include most of the required aspects and could inform a framework of best practice for South African PWs, is the model designed and implemented by Cape Mental Health (CMH)[5] at its Training Workshops Unlimited centres, as outlined in a poster presentation by Terreblanche[34]. This model consists of a series of structured training programmes suitable for service users at different levels of functioning that form a training and career path that allows for progression, exit opportunities and continued support. This is complemented by self-

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advocacy structures to allow service users to evaluate and advise on service delivery. This programme has won various national awards for innovation and is acknowledged as a best practice programme by SAFMH and DSD. The reason this programme could not simply be rolled out to the rest of the SAFMH PWs was that it had only been implemented in Cape Town thus far and did not have buy-in from the rest of the SAFMH PWs as a best practice model for all SAFMH PWs. It developed in an urban area in response to the needs of a specific group of service users and based on the funding available to CMH. SAFMH therefore identified the CMH Model as a starting point for the development of a national SAFMH framework for best practice service provision for adults with ID.

1.4 Research Question

What could be a transformation strategy (including a framework of best practice for and implementation strategy) for PWs operated by SAFMH in South Africa?

1.5 Purpose of the study

The purpose of the study was to assist SAFMH Workshops with transformation in order to align them with the Department of Social Development (DSD) Policy on PWs[19] and to increase sustainability to enable best practice service provision to persons with ID at all SAFMH PWs across South Africa.

1.6 Aim and objectives

The aim of this study was to draw on the experience and expertise of management and service user representatives of existing PWs for persons with intellectual disability (ID) to develop a transformation strategy (including a national framework of best practice and an implementation strategy) for the 31 South African Federation for Mental Health (SAFMH) Protective Workshops (PWs).

The objectives were:

- To explore the opinions of key role players in SAFMH PWs on the key elements in the development of a framework of best practice for PWs informed by the Cape Mental Health best practice model.
- To establish the nature of service provision that could form part of a framework of best practice for SAFMH PWs.
- To develop a national framework of best practice for SAFMH PWs.
- To develop an implementation strategy that could guide the transformation of workshops from current status to new best practice model status.
- To identify potential income streams to increase the financial sustainability of the newly developed SAFMH PW framework.

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1.7 Delimitation of this study

This study focussed on the transformation of PW operated by the SAFMH with co-researchers consisting of managers and service user representatives of these SAFMH PWs only. It was not aimed at the macro environment of the PW sector in South Africa.

It was agreed by the CIG and the SAFMH Board that the CIG will develop a framework of best practice and an implementation strategy. The costing, development of training materials, management and the implementation at PWs was agreed to fall outside the scope of this study.

1.8 Overview of chapters

This thesis will set out the study in terms of Literature review (Chapter 2), Methodology (Chapter 3), Findings (Chapter 4) and Discussion and conclusion (Chapter 5).

In Chapter 2 (Literature Review) the researcher argues that the lack of transformation is due to a lack of understanding by PW managers and staff of the expectations for transformation and the human rights of persons with ID. To ensure alignment with a human rights approach at maximal level of integration, the chapter will provide an overview of the theoretical and legislative backgrounds, previous research done and programmes currently implemented that could advise the development of a framework of best practice and implementation strategy for SAFMH PWs.

Chapter 3 (Methodology) will inform on the methodology of action research with co-operative inquiry and explain how it was applied in this study. It will also discuss the analysis and ethical considerations.

Chapter 4 (Findings) will state the findings including new knowledge that emerged from the analysis. It will further inform on the transformation strategy (consisting of a service delivery framework and an implementation strategy) that was developed during this study for the transformation of SAFMH PWs.

Chapter 5 (Discussion and conclusion) will provide a discussion of the findings, recommendations, will discuss limitations of the study, provide directions for future research and a conclusion.

1.9 Conclusion

This chapter served as an introduction to the study. It provided information on SAFMH and the history and background of PWs in South Africa. It further discussed the transformation challenge for PWs and provided information and criticism relating to the model for transformation prescribed by DSD. The commissioning of the study was explained to provide the context for the study. The research question, purpose of the study, aim and objectives were confirmed followed by an overview of the chapters in this thesis. The next chapter (Chapter 2) will provide the outcome of the literature review.

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Chapter 2 LITERATURE REVIEW

2.1 Introduction

The previous chapter served as an introduction to the study and provided the background of PWs, explained the SAFMH context and the transformation challenge that resulted in the commissioning of this study. It further outlined the research question, purpose of the study, aim and objectives and provided an overview of the chapters in this thesis. This chapter will focus on the outcome of the literature review.

A literature review was done to inform the development of a framework of best practice and implementation strategy for SAFMH PWs.

This chapter will focus on the severity of ID and levels of functioning, the level of vulnerability of persons with ID, their support needs and right to self-advocacy, choice and preference.

This section further report on literature reviewed to determine the human rights and legislative background to service delivery to persons with intellectual disability (ID), to define and explore theoretical frameworks for best practice, to explore factors that may influence successful transformation, to search for evidence of best practice programmes to include in the framework and to determine the best methodology to use for the study.

A combination of sources was reviewed including books, journal articles, presentations, legislation, and publications by the South African Government and websites of disability sector service providers and organisations of disabled persons. The findings of the literature review relating to different aspects of service delivery to persons with ID will be described in this chapter. A description of the definition of and criteria for a best practice service for persons with disabilities will be provided, followed by theoretical frameworks that could advise the development of a framework of best practice. This will be followed by a description of the human rights and legislative backgrounds to service provision for persons with intellectual disability (ID) and protective workshops (PWs) in South Africa. The chapter will further describe factors that may influence the successful transformation of PWs and describe programmes that could possibly be included in a best practice programme for SAFMH PWs. It will highlight evidence found in the literature of best practice programmes in existing South African PW programmes. Lastly, it will describe the methodology best suited to developing a best practice service provision framework for adults with ID in South Africa followed by a conclusion to the chapter.

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2.2 Theoretical frameworks that could inform a framework of best practice

In the search for best practice service delivery frameworks for persons with disability (including ID), two models were identified that could advise a framework of best practice, viz.: the World Health Organisation's Community Based Rehabilitation Model[4] and the Vona du Toit Model of Creative Ability[14]. These 2 models will be discussed in more detail below.

2.2.1 The World Health Organisation's Model for Community Rehabilitation (WHO CBR)

The World Health Organisation (WHO)[4], in its guidelines on community-based rehabilitation (CBR)[4] refers to 5 key components with 5 key elements each that should be included in community-based service provision to persons with disabilities and their families. The 5 components to be included in community-based services are: Health, Education, Livelihood, Social and Empowerment. The CBR Matrix[4] in Figure 2.1 below gives an overall visual representation of the CBR components and elements.

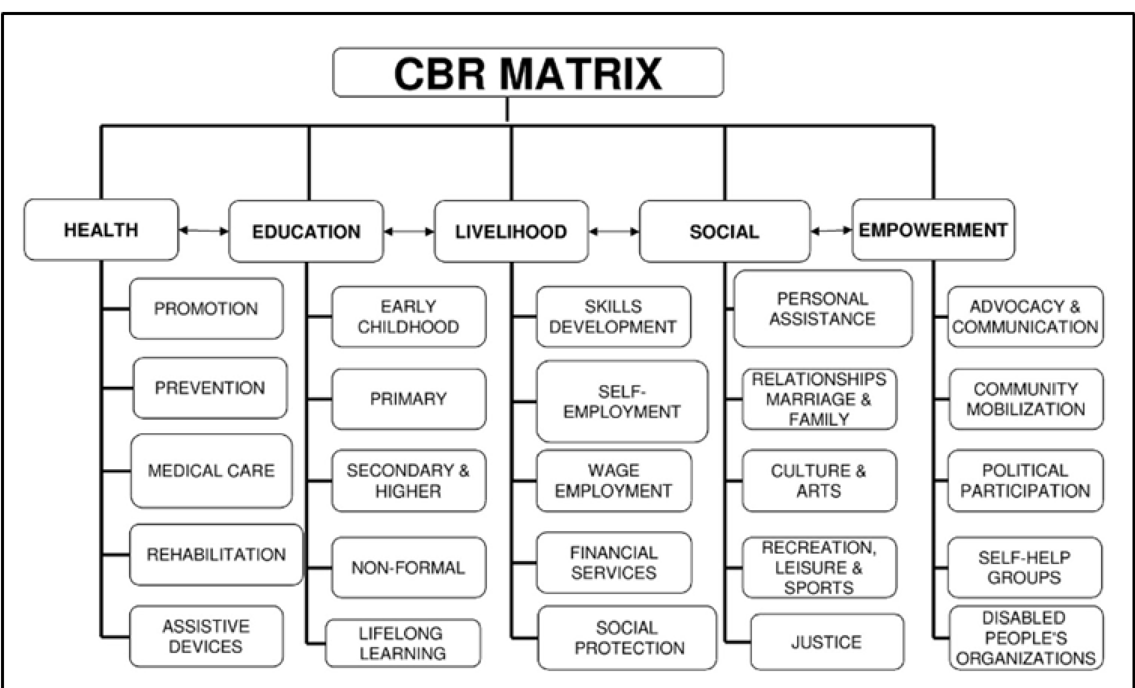

Figure 2.1 The WHO CBR Matrix[4]

The CBR model is valuable in guiding the development of new service delivery frameworks to ensure that all areas of development are covered to ensure a holistic and developmental approach and includes collaboration of all stakeholders. The Health Component describes the need for health promotion, prevention of disability and/or further disability, the availability of medical care and rehabilitation services, and assistive devices to enable persons with disabilities to participate. The Education Component describes the importance of education throughout the lifespan of a person

with disability from early childhood development to lifelong learning in adulthood. The Livelihood Component confirms the importance of financial independence through skills development, income generation, employment, self-employment or social security. The importance of inclusion in family and community life with access to arts and culture, sport and recreation activities are highlighted in the Social Component, with further emphasis on the need for personal assistance and access to justice. Finally, the Empowerment Component confirms the importance of advocacy and communication, community mobilisation and political participation to raise awareness of the rights of persons with disabilities and to ensure effective service provision. The importance of persons with disabilities to organise themselves into self-help groups and disabled people's organisations are also emphasised as part of empowerment.

The CBR stakeholders are identified (from closest to furthest removed from the person) to be the person with disability and his/her family, the community, community leaders, teachers, health and community workers, local government, NGOs and disability groups, national government, political leaders and the media.

The main disadvantage of the CBR model in the transformation of PWs is that it is geared towards a community strategy towards disability rather than a developmental person centred programme for persons with disabilities. Although the different elements contained in the CBR Model could inform the different training aspects to be included in the new framework, the CBR Model could therefore not be adopted as the transformation model for PWs.

2.2.2 The Vona du Toit Model of Creative Ability (VdTMoCA)

The VdTMoCA[14] is an occupational therapy practice model originating from South Africa. This model could guide service provision to persons at different levels of functioning and was used successfully by De Witt[35] in intervention with persons with mental disabilities at different levels of functioning. This model is based on the belief that motivation governs action and action is an expression of motivation. It describes nine levels of creative ability (refer to Table 2.1) based on levels of motivation and action.

According to the model, human beings progress through levels 1 – 9 in a sequential manner and can either progress or regress based on life experiences and exposure to new challenges. The VdTMoCA[14] was further developed by De Witt[35]. She describes four occupational performance areas to be addressed and developed in service delivery: viz. personal management, social ability, work ability and constructive use of free time. The rationale is that intervention should start at the client's current level of creative ability and participation, and develop to facilitate progress towards the person's maximum creative potential. This is influenced by factors such as intelligence, mental health, and

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opportunities within the environment, personality and security. Growth does not occur automatically, but through exertion of the person's creative boundaries through creative effort. This means that a person will not progress to a higher level if not exposed to challenges and higher expectations.

Table 2.1 The levels in the Vona du Toit Model of Creative Ability (VdTMoCA)[14]

Level	Motivational Level	Action Level	Level of participation
9	Competitive contribution	Society-centred	Group 3: Behaviour and skills development for self-actualisation: develop leadership skills, capable of developing new products, methods, technologies, problem solving and dealing with complex situations
8	Contribution	Situation-centred	
7	Competitive	Product-centred	
6	Active participation	Original	
5	Imitative participation	Imitative	Group 2: Behaviour and skills development for norm compliance: developing skills to live and be productive in the community and comply with society's norms. Occupational performance is limited and persons lacks the ability to be occupationally productive
4	Passive participation	Experimental	
3	Self-representation	Explorative	
2	Self-differentiation	Incidental constructive/ destructive	Group 1: Preparation for constructive action: development of physical function, who they are and how they can move their bodies
1	Tone	Pre-destructive	

This has implications for a proposed SAFMH framework in that it would have to build in challenges and higher expectations to service users as part of the programmes offered to achieve development and progress in its service users.

The VdTMoCA[14] describes 3 phases within each level: firstly the therapist-directed phase, then the patient-directed phase and lastly the transitional phase. During the therapist-directed phase a high level of input is required from the therapist to facilitate participation for the client to explore his/her abilities and occupational performance. During the patient-directed phase the client has gained a level of competence and requires less input from the therapist. During the transitional phase the client has achieved the performance at the current level and demonstrates signs of motivation and skills of the next level.

From the frameworks described above it is evident that a framework of best practice for PWs for persons with ID should offer a spectrum of holistic services at different levels to suit the functionality, abilities and needs of all persons registered as service users as described in the VdTMoCA[14] and the WHO CBR model[4]. The programmes should have a developmental approach and should promote active participation, self-advocacy and

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progress toward maximum level of integration and independence in mainstream society. PWs are currently situated as a paralelle stream for persons with ID where they participate in activities simulating mainstream society i.e. work (simulating the open labour market). Training materials and methods used should suit the special educational needs[36,37] of the service users and appropriate levels of challenges and support at all levels of intervention are critical.

2.3 Key human rights and legislative backgrounds to service provision for persons with intellectual disability (ID) and protective workshops (PWs) in South Africa

Best practice services are defined as initiatives contributing to the removal and/or reduction of barriers to the inclusion of persons with disabilities in all aspects of life and which could be considered for replication, upscaling and further study[15].

The criteria to qualify best practice service require that the service must:

- adopt a human rights-based approach.
- increase awareness and understanding of disability to promote positive attitudes towards disability to reduce stigmatization.
- be results-based and produce a measurable change in the quality of life of its service users, including a monitoring and evaluation system and data on the participating persons with disability.
- be appropriately resourced financially and in terms of human resources.
- be sustainable.
- be replicable and able to show that the product and/or process could be reproduced or adapted to be implemented in different contexts.
- involve effective partnerships including, inter alia, government, non-government organisations (NGOs), academia and disabled persons' organisations (DPOs).

South Africa has some of the most progressive legislation[38] on the rights of persons with disabilities (including persons with ID) in the world. Amongst these are the South African Constitution[26], the White Paper on an Integrated Disability Strategy[28] the Employment Equity Act (55 of 1998)[20] and the Mental Health Care Act (17 of 2002)[39]. In summary, these documents state that persons with disabilities (including persons with ID):

- have equal rights and status as all other citizens and
- have equal access to opportunities as all other citizens in all spheres of life including, but not limited to, education, social welfare, employment and community integration.

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In addition to the South African legislation mentioned above, South Africa signed and ratified the United Nations Declaration on the Rights of Persons with Disabilities (UNCRPD)[13]. The principles of the UNCRPD (Article 3) include, amongst others, the respect for dignity, the freedom to make own choices, independence, non-discrimination, full and effective participation and inclusion in society, equality of opportunity, and accessibility.

Further rights described in the UNCRPD relevant to the development of a service provision framework for a day programme for persons with intellectual disability are their right to:

- freedom from exploitation, violence and abuse (Article 16), prescribing to service providers how to treat their service users with respect and dignity.
- being included in the community (Articles 19 and 30), setting the expectation that all programmes should be aimed at maximum levels of integration into the community.
- support and assistance with decision making and handling of their affairs by persons acting as intermediaries (Article 20).
- privacy (Article 22), impacting on the manner in which service providers deal with personal care and sensitive information.
- access to education at all levels, including vocational training, adult education and lifelong learning with the appropriate level of support provided (Article 24).
- access to habilitation and rehabilitation services and programmes (Article 26) to be included in service provision.
- access to work and employment including vocational training and reasonable accommodation, opportunities to gain experience in the open labour market and access to self-employment and entrepreneurship opportunities (Article 27).
- access to social protection, poverty reduction, training, counselling and respite care programmes (Article 28).
- self-representation (article 29), to guide and support service providers to support service users in self-advocacy.
- access to cultural, recreation, leisure and sport activities (Article 30), to ensure a holistic approach to the person.

The implication of the above on a best practice service framework is that all programmes must make provision for the adherence to all these rights to ensure that it is aligned with legislation.

Two acts that could assist PWs with the integration of persons with ID into the open labour market, are the Broad Based Black Economic Empowerment (BBBEE) Act (no. 53 of 2003)[3] and the Employment Equity (EE) Act (no. 55 of 1998)[20] In these acts, persons

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with disabilities are identified as a designated previously disadvantaged group that was excluded from equal opportunities in the past. The EE Act describes affirmative action to ensure that persons with disabilities, who are equally qualified and suitable for a job, be appointed. The BBEE Act uses a scorecard to measure the transformation of corporates and organisations to reflect the population of South Africa in its ownership (shareholders), management structures, procurement, enterprise development and social investment portfolios. A company could therefore score higher on the BBBEE scorecard by getting involved in enterprise development through funding PWs.

Besides promoting the human rights of persons with disabilities, South African legislation and government policies describe a set of requirements to service providers in delivering services to persons with disabilities (including intellectual disability) registered at PWs. The White Paper on an Integrated National Disability Strategy[28], the DSD Policy on Disability[30] and the DSD Policy on PWs[19] are the main policy documents in this regard. The requirements for service provision to persons with disability (including persons with intellectual disability) by South African PWs can be summarised as follows:

PWs should:

- follow a people-centred and developmental approach.
- provide empowering and capacity building programmes with a balance between psycho-social and economic empowerment.
- create access to economic life and activities, work skills training, entrepreneurial and self-employment opportunities through career pathing.
- provide appropriate support services.
- facilitate full and equal inclusion into mainstream society through all services.
- make provision for self-representation and self-advocacy by service users and provide services in consultation with service users.
- adhere to minimum standards prescribed by DSD.
- operate as viable and self-sustainable units through partnerships and securing additional sources of funding to complement government subsidies.

2.4 Factors influencing the successful transformation of PWs

The DSD Study on PWs[23] identified the factors that could influence successful transformation of PWs to include strategic leadership and management structures, a credible and uniform model, the introduction of service delivery structures and processes, as well as operational policies and systems.

According to Oldman et al.[40], in a case study on the successful transformation in Canada of a sheltered workshop (the term often used for PWs internationally), the success was due to a felt need for change, strong leadership, encouragement, outcome monitoring,

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financial support, guidance and consultation by experts, and by following a systematic change process.

Based on the above, the researcher argues that DSD (as the custodian of South African PWs) could have done more to facilitate a mind shift in the management and staff of PWs, provide a systematic transformation process with deliverables and timelines, introduce incentives for transformation initiatives by PWs, and make subsidies available aligned to the achievement of set transformation outcomes and minimum standards.

2.5 Programmes to include in a best practice framework for PWs

The programmes to include in the framework of best practice should be selected to suit the unique needs of persons with ID. The literature review therefore included a review of the factors determining the service needs of persons with ID and a search for best practice programmes currently implemented internationally.

2.5.1 Factors that determine the service needs of persons with ID

When looking at programmes to include in a best practice framework for service delivery to persons with ID, a few factors were explored in the literature to determine the service needs of persons with ID. These factors include the severity of the disability and level of functioning, level of vulnerability, support needs and the right to self-advocacy, choice and preference.

Severity of ID and Level of Functioning

The Fifth Diagnostic and Statistical Manual of Mental Health Disorders (DSM-5)[17] defines intellectual disability as a chronic developmental disorder that involves impairments of general mental abilities that impact adaptive functioning in the domains of conceptual, social and practical functioning with an onset during the developmental period. The level of severity is indicated as mild, moderate, severe or profound, based on how well an individual copes with everyday tasks. The diagnosis of intellectual disability is made based on standardised intelligence tests and clinical assessment of adaptive functioning. The Diagnostic and Statistical Manual of Mental Health Disorders (DSM-5)[17] indicates the level of severity of intellectual disability based on the adaptive functioning of the person and how he/she copes in everyday activities in the domains of conceptual, social and practical functioning.

Based on the levels of adaptive functioning, the DSM-5 classifies intellectual disability into Mild, Moderate, Severe or Profound. Persons with **mild ID** (85% of persons with ID) are mostly self-sufficient with minimal support in the areas of living. Persons with **moderate ID** (10% of persons with ID) may have adequate communication skills, but complexity is limited. They are able to perform most self-care activities, but need instruction and support. They usually need assistance with social cues, social judgement

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and social decisions. Additional support may be required in living (such as provided in group homes) and working. Persons with **severe ID** (3% of persons with ID) have very basic communication skills. Self-care activities require daily assistance and they will need supervision for safety. Persons with **profound ID** (2% of persons with ID) are dependent on others for all aspects of daily care in the form of 24-hour care and support. Communication skills are quite limited and they usually have co-occurring sensory or physical limitations.

The average abilities of persons in the different ID severity levels are summarised in Appendix B[1,12,17,37,41-43]. Adaptive functioning (as described in Appendix B) covers a wide spectrum of abilities and limitations that need consideration in service design to ensure suitable programmes and intervention to all service users.

From the review of relevant legislation and the UNCRPD[13] the researcher concludes that all persons with intellectual disability should have access to vocational training, employment and community integration opportunities and career pathing at an appropriate level of intervention through specialised training methods and with the appropriate level of support despite the severity of the disability. This is supported by Wehman[44] who states that all persons with disability have the right to employment in an integrated setting despite the severity of the disability.

Based on the different functionality and needs of the service users with different severity levels of ID, it was concluded that even though comprehensive services to all the different ID severity levels need to include all the aspects discussed above, it would not be possible to design one service that would meet the needs of all service users with ID. It was thus argued that a framework of best practice for PWs would have to include programmes at different levels offering different levels of support and challenges appropriate to the level of functioning of persons functioning according to the different severity levels of ID.

The level of vulnerability of persons with ID

By offering services at the highest level of community integration possible, service users with ID are challenged by exposure to new and unfamiliar situations and increased interactions with people. This is aligned with the VdTMoCA[14] that requires services to provide challenges and higher expectations to facilitate development and progress.

However, this often creates fear in the minds of parents/caregivers that service users with ID would be at risk[45-48,48,49] based on the fact that persons with ID are often more vulnerable to sexual abuse, physical abuse, neglect and financial exploitation due to their lack of knowledge, low self-esteem, lack of self-protection skills and dependence on others for personal care[38,49]. The right of persons with ID to be protected against abuse is acknowledged in the Mental Health Care Act of 2002[39], the DSD Policy on Disability[30] and the UNCRPD[13].

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The perceptions of parents are often that their adult children with intellectual disability would be safer in a sheltered or protected environment[47,50], but the literature review provided evidence of abuse and exploitation also taking place within the sheltered care settings for adults with ID[49,51].

Brown, Shiraga and Kessler[50], after reviewing the records of 50 adults with significant disabilities in integrated environments, concluded that vulnerable persons are the safest in an integrated environment where they participate alongside peers without disabilities who are not paid to be with them.

In their attempt to provide a safe haven to persons with ID, PWs are often seen as segregating and isolating the service users and, as such, being a barrier to integration[47]. This is in contrast to the view of Wehman, Revell and Brooke[18] that persons with disabilities need to be connected to formal and informal community networks for acceptance, growth and development. To achieve protection and integration for adults with ID and to increase their safety in all environments, the researcher agrees with Van der Zande[48,52] who recommends that it is best to provide persons with intellectual disability with information on setting boundaries and how to get help, and to teach them self-protection and self-defence skills.

The researcher concluded that even though persons with ID are more vulnerable and need protection against abuse and exploitation, protection measures should not stand in the way of integration, but rather be provided for within service delivery models to ensure maximum level of integration.

Appropriate levels of support could assist in ensuring the safety of persons with ID.

The support needs of persons with ID in service delivery

The Centre for Developmental Disability Health at the Monash University[53] proposes that individual support needs depend on individual factors including personality, coping skills, the presence of other disabilities, the amount of support offered by family, friends and the community and the situational demands on the person with ID. Different service users with ID will therefore need different levels of support in different areas at different levels of intensity.

The DSM-5[17] acknowledges the need for on-going support to prevent adaptive deficits from limiting functioning for persons with ID. Support for persons with ID is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD)[1,12] as resources and strategies necessary to promote the development, education, interests and well-being of a person with intellectual disability and can be provided by family, friends, community members, professionals or agencies.

According to the AAIDD, individualised support for persons with intellectual disability can facilitate improved personal functioning, promote self-determination and

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integration, enhance well-being, and lead to community inclusion – and therefore provide access to their rights as outlined in the UNCRPD[13].

In contrast to the measurement of adaptive functioning that focuses on the limitations of the person, the support approach questions what it would take to enable the person with intellectual disability to achieve a goal and how that support could be provided[8].

Areas in which persons with ID may require support

Evidence of the support needs of persons with ID was found in articles on the Supports Intensity Scale (SIS)[12] and the Instrument for the Classification and Assessment of Support Needs (I-CAN)[8], two assessment tools to determine the support needs of individual service users with ID. Both the SIS and the I-CAN state that support needs are specific to each individual, should be based on an individual support assessment and should lead to specific strategies and services to optimise individual functioning. Both also acknowledge that support needs will change over time and should therefore be reviewed and adapted regularly.

The SIS identified nine key activity areas while the I-CAN identified 2 domains with 11 activity areas in which persons with intellectual disability may require support as can be seen in Table 2.2 below:

Table 2.2 Support areas as per the SIS[12] and I-CAN[8]

SIS	I-CAN
Key activity areas: 1. Home Living 2. Community Living 3. Lifelong Learning 4. Employment 5. Health and Safety 6. Social 7. Exceptional medical 8. Behavioural	Support Domains: Domain 1: Health and Well Being 1. Physical Health 2. Mental & Emotional Health 3. Behaviour of Concern 4. Health & Support Services Domain 2: Activities and Participation 1. Applying knowledge, general tasks and demands 2. Communication 3. Self-care and Domestic Life 4. Mobility 5. Interpersonal interactions & Relationships 6. Lifelong Learning 7. Community, Social & Civic Life

The intensity of support needed by persons with ID

The levels of support identified by the SIS (4 levels) and I-CAN (5 levels) define the support needed according to the frequency and intensity, and show similarities as can be seen in Table 2.3 below.

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Table 2.3 Intensity levels of support as per the SIS[12] and I-CAN[8]

Support Intensity Scale		I-CAN	
1	Intermittent: as needed during times of transition and stress	1	Occasional / Managed
2	Limited: Consistent time-limited	2	Monthly / Minor
3	Extensive: Long-term support	3	Weekly / Moderate
4	Pervasive: Consistent high intensity support	4	Daily / Extensive
		5	Constant / Pervasive

A pilot study done by Carter[54] using the SIS with 181 participants with ID in the United States of America indicated that the average percentiles for support needs activities in the six areas of living for the participants ranged from 61.2% to 78.4%, as can be seen in Figure 2.2 below. This confirms that the support needs of persons with intellectual disability are high in all areas of living.

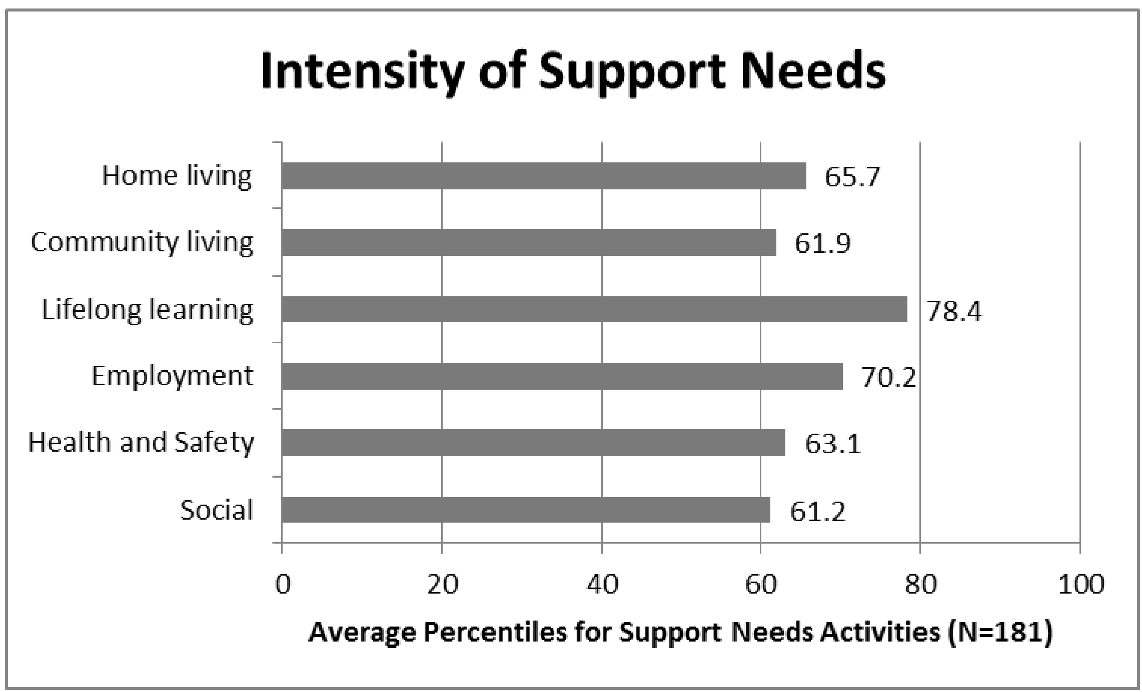

Figure 2.2 Intensity of support needs study results[54]

Aligned with Carter's findings, Brown, Shiraga and Kessler[50], after reviewing the records of 50 adults with significant disabilities in integrated environments (including employment, living, recreation and community participation), concluded that none of the persons reviewed would have been successful without the comprehensive support

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of families, job coaches, co-workers without disabilities, taxpayers (state funding) and others.

The support currently provided to persons with ID at SAFMH PWs (as evident from feedback from the PW Managers at the February 2011 workshop) focus mainly on support by the PW staff to the person with ID to cope within the PW environment in the areas of social interaction, health and safety and to participante in the activities offered by the PWs that could include contract work, recreation and arts and craft activities. Only 3 PWs offered support by job coaches or social workers to persons with ID in lifelong learning opportunities and employment in the open labour market. It was reported that the job coaches were instrumental in integrating persons with ID into the open labour market and the community. It was reported that the support currently provided was not sufficient due to the high staff to service user ratio at most PWs where one staff member needs to support a group of up to 30 service users in a group activity.

From the above it is clear that a best practice service framework for adults with ID should include appropriate levels of support in all aspects and across all levels of service provision to enable the service users to participate and develop towards maximum level of functioning and integration.

Self-advocacy, choice and preference

Another factor that could influence service delivery is the right of persons with ID to speak for themselves and to indicate choice and preference.

The researcher argues that most PWs do not empower their service users to speak for themselves, but regard them as children who need someone else to make decisions on their behalf.

According to the DSD Draft Report of the Audit of PWs[23] most PWs provide a single service that does not allow for choice or indicating own preference.

Under Article 12 of the UNCRPD[13] persons with ID have the right to legal capacity and autonomy and should have access to the necessary support to enable them to make decisions appropriate to their circumstances. For persons with ID this means moving away from substitute or surrogate decision making (that is aligned with the belief that persons with ID are children for life and not able to make informed decisions as described by the American Assosiation on Intellectual Disability and Developmental Studies[12]) to supported decision making (that implies that they can make decisions with suitable levels of support and information provided[55]).

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Werner[55], after reviewing 27 manuscripts on decision making by persons with ID, concluded that:

- supported decision-making for persons with ID needs to be improved through the education of persons with ID to develop better decision making skills, taking into account the abilities and learning style of the individuals.
- services at day programmes should be designed to allow for choice and self-determination through flexibility in daily routines and person centred planning.
- staff and caregivers should be trained to provide the necessary support and to communicate appropriately with the person to allow for supported decision making; this may include visual aids or alternative communication methods.
- staff and caregivers should allow persons with ID to make mistakes and learn about consequences.
- self-advocacy groups supported by service providers can play an important role in facilitating improved decision making by persons with ID.
- persons with ID should be included in collaborative research studies to acknowledge their right to self-determination.

Brown, Shiraga and Kessler[50] concluded that integrated settings enhance personal choice options for persons with ID. In developing a framework of best practice for service delivery to persons with ID, it means that the programme design should allow for choice, training in decision making skills and should provide the necessary support to enable them to make informed decisions on participation.

The need for support and advocacy as an integral part of service delivery to adults with mental disabilities at all levels of intervention was evident in the review by Hall[56] to ensure social inclusion and belonging. She argues that persons with intellectual disability need practical, social and emotional support and that the lack thereof (amongst other reasons) caused many to decide against being in paid employment or independent accommodation. Hall[56] concluded that for persons with intellectual disability to feel attached, valued and have a sense of belonging, they should be part of activities, networks and social spaces within mainstream society with the necessary support and through advocacy. Equally important, Krstovski et al.[57] underlines the role of self-advocates evaluating and advising on service users' needs in day services offered by non-government organisations to ensure quality service provision.

In alignment with the right to speak for themselves and being included in decisions made relating to service delivery, is the slogan often used by self-advocacy groups of persons with disabilities: "Nothing about us without us"[58]. With its origin in Europe, this became the slogan of the disability rights movement in South Africa in the early 1990s.

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2.5.2 Best practice programmes currently implemented nationally and internationally

In considering the programmes to include in the framework of best practice, a review of good practice services for persons with intellectual disability offered by non-government organisations and state institutions nationally and internationally demonstrated a number of requirements. This includes respite care, activity programmes, independence training, pre-vocational and vocational training, supported employment, self-advocacy programmes and therapy services.

Respite Care

Respite Care[42,51,59,60] of persons with ID is defined by Canavan in the MLitt BM study[61] as short-term or temporary care of a person with ID to provide relief to the regular caregiver (who is often an aging family member[42]). The purpose of respite care is to maintain the carers in their roles and improve their caring capacity, and to provide benefits for the persons with ID.

In a publication on best practice respite care services for persons with ID, Drudy (in the foreword to the MLitt BM study[61]) states that respite care should, in addition to providing relief to carers, also provide positive opportunities for persons with ID to interact with their peers, to achieve a measure of independence, and to enjoy relationships with persons outside their immediate family circle.

Respite care provided by PWs is for a few hours per day in the form of a day programme. Relieving the caregivers from their care duties in this way could enable the carers to attend to their own needs or fulfil their own aspirations[42].

Activity programmes

Activity programmes[60,62,63] are offered to persons with ID who are not at the level of development to be included in a formal work environment. Activities such as arts and crafts, sport and recreation, educational games and outings are used to develop the service users in a group context. It is often offered in conjunction with independence training, as discussed below.

Independence training

These programmes[57,62,63] focus on the training of basic self-care tasks (dressing, eating, personal hygiene tasks), community skills (accessing community resources like libraries, shopping centres, recreation facilities, etc.), public transport, money management, communication skills and more to increase the level of independence of the service users. This is done in controlled familiar settings first, before the acquired skills are generalised to more integrated settings with the required level of support per individual.

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Prevocational and vocational training

The pre-vocational and vocational training programmes[5,47,63-69] outlined in the literature reviewed are offered to introduce persons with ID to a formal work setting. The pre-vocational programmes focussed on aspects including good work habits, appropriate behaviour in the work place, basic work skills and the use of hand tools, following instructions and building up endurance to be able to remain in a work setting for a full work-day. The work activities are not generally part of production requirements and deadlines are not set for completion.

The vocational training programmes described in the literature reviewed include structured work activities in the form of sub-contract work in production lines with set targets and deadlines. It further includes a wage or stipend based on the individual's contribution to production.

Supported Employment (SE) services

Supported Employment programmes[18,44,50,70-77] are offered as the intervention of choice by service providers that prefer real work settings for vocational rehabilitation. Supported employment programmes include the preparation of the candidate with ID for work placement, job coaching and assistance with searching, application and interviews to secure employment. It further includes assistance with negotiations regarding work conditions, remuneration and reasonable accommodation needed by the person with ID.

Job Coaching is described as an on-going service including support for the employee with ID and the employer, fellow employees and the family as needed.

From the results of a study done by Van Niekerk et al.[11] Supported Employment of persons with ID needs the highest levels of intervention in the first three months of post placement after which intervention decreases to reach a maintenance level from the sixth month of post placement, as can be seen in Figure 2.3.

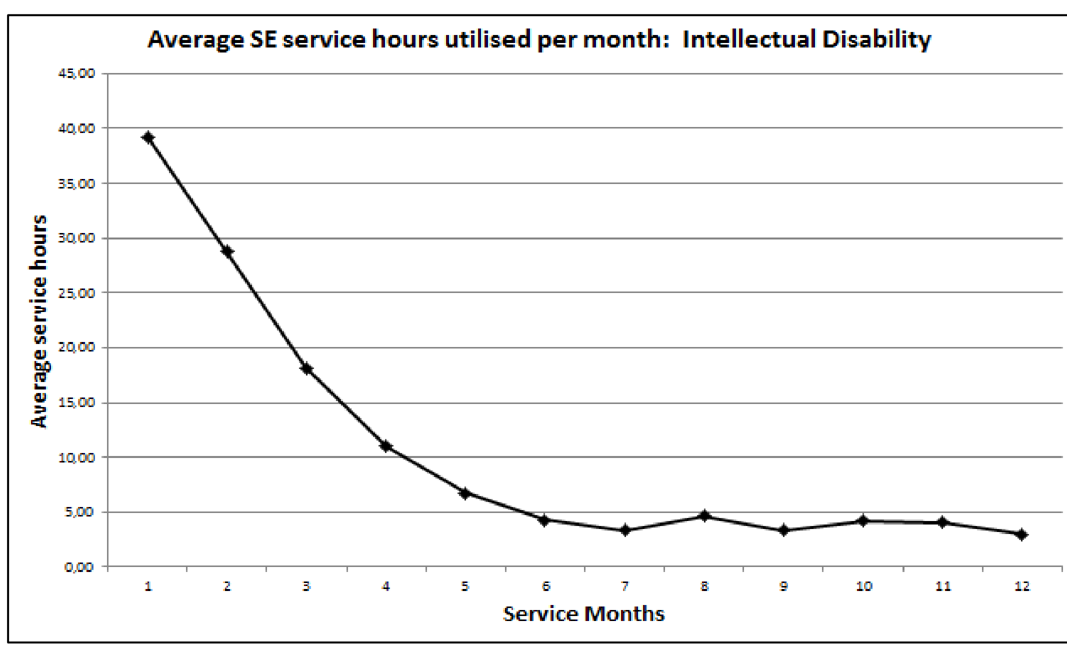

Figure 2.3 Average Supported Employment Hours utilised per month for the first 12 months after placement[11]

The study further described the job coaching provided to persons with ID to include the following components in the percentages demonstrated in Figure 2.4 below. Services provided under the component named "Other" mainly focussed on advocacy and assertiveness training relating to the rights of persons with ID in the workplace.

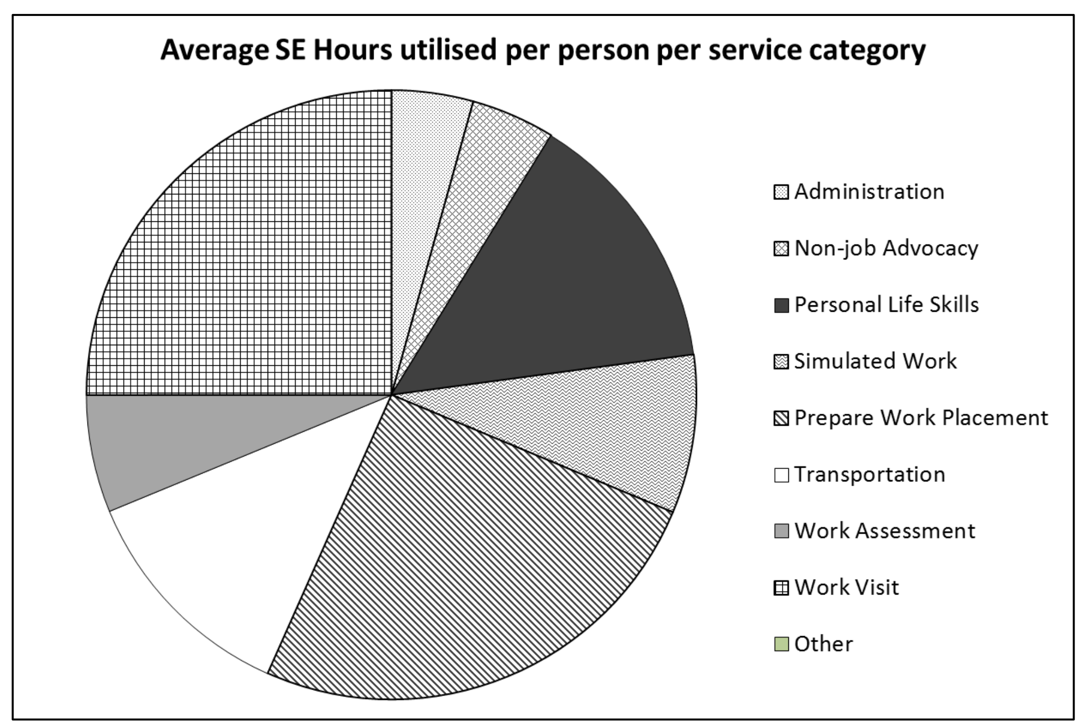

Figure 2.4 The SE components utilised during the first 12 months after placement[11]

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Brown, Shiraga and Kessler[50] in a study on Supported Employment confirmed that professional support in employment is essential and refers to the extent and kinds of assistance a job coach provides that would not be required if a worker were not disabled or were less disabled.

Self-advocacy programmes

The self-advocacy programmes[55,55,56,71,78-80] described in the literature reviewed, aim to empower service users with ID to speak for themselves and to represent persons with ID on different forums. This includes training of persons with ID on their rights and responsibilities, and outlines the essential role of the supporter in supporting self-advocates with ID to represent themselves on different forums including service user forums, boards of organisations, and during meetings with government departments and other stakeholders.

Two types of supporters for self-advocates are described, namely an individual supporter and a group supporter. An individual supporter supports a person with ID when attending a meeting consisting mainly of persons without ID to manage and reduce anxiety levels, clarify procedures and expectations, and assist the service user to formulate responses. The individual supporter may also assist with logistical arrangements including transport and accommodation, and with reasonable accommodation that may include an easy-to-read agenda and minutes, more rest breaks, extra explanations and reformulation of questions as needed by the service user with ID to optimally participate in the meeting. A group supporter, on the other hand, could perform the same support activities as the individual supporter but for a group of service users in a meeting consisting of mainly persons with ID.

Therapy services

The therapy services[28,36,81] described and offered by service providers include occupational therapy, physiotherapy and speech and language therapy. These services are offered both in groups and on an individual basis based on the needs of the service users.

2.6 Methodology best suited to develop a transformation strategy PWs for adults with Intellectual Disability in South Africa

The review of the literature for this purpose included studies with a similar aim of developing a new framework or adapting an existing model for service delivery. It was found that Action Research[82] with Co-operative Inquiries[83] as methodology was used successfully to develop or adapt service delivery models through inquiries with co-researchers (staff professionals and/or service users) from within their specific sectors to find solutions for their sector-specific challenges in the following reviewed studies:

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- DeVore and Russell[84] used AR with co-operative inquiry to develop a model to facilitate the expansion of inclusive early childhood education and care practices through data collection and action planning during focus groups and community meetings. The outcome of the research was a model that offered better preschool options for young children with disabilities through social recognition by the School District Offices and technical assistance through state grant funding.
- Zeits et al.[85] developed a new model of care for older persons using an AR with co-operative inquiry approach by facilitating five workshops over a 4-month period with volunteer older persons, clinicians and facilitators. The new model brought about a better awareness, understanding and acceptance of the experiences and expectations of care of both clinicians and consumers.
- Mash[86] used AR with co-operative inquiry in a South African study to successfully transform the World Health Organisation's model for distance education and materials on common mental disorders for general practitioners to suit the South African context through co-operative inquiry workshops and meetings with South African medical practitioners as co-researchers.

All of the above-mentioned studies aiming to bring about change in service delivery models confirmed that AR with co-operative inquiries was the best suited and preferred methodology for this study.

Further support for the application of AR with CI was found in Kimberly and DeTardo-Bora[87] who argued that AR is the suitable research design where change is the goal of the research study. They described it as diverging from the power-control model of research with a tentative, evolving and cyclical nature while it goes beyond the discovery of knowledge in its change-orientation. Reason stated that AR with CI brings together service providers and service users who best understand the practice issues and are therefore best positioned to bring about change[16,88,89].

2.7 Conclusion

The literature reviewed confirmed the definition of and criteria for best practice service programmes for persons with disability, the importance of the legislative and human rights backgrounds to service delivery to persons with ID and their service needs. It further described factors that could influence successful transformation, existing programmes that could be considered for inclusion in a framework of best practice and the methodology best suited for this study.

The next chapter will describe the methodology used in this study.

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Chapter 3 METHODOLOGY

3.1 Introduction

The previous chapter provided the outcome of the literature review. It confirmed the definition of and criteria for best practice service programmes for persons with disability, the importance of the legislative and human rights backgrounds to service delivery to persons with ID and their service needs. It further described factors that could influence successful transformation, existing programmes that could be considered for inclusion in a framework of best practice and the methodology best suited for this study.

This chapter will introduce the theoretical background and practical utilisation of the research design and methods used in this study. The aim of this study was to collaborate with management and service user representatives of existing PWs for persons with Intellectual Disability (ID) to develop a transformation strategy in the form of a framework and an implementation strategy for the 31 South African Federation for Mental Health (SAFMH) Protective Workshops (PWs).

The study design used in this study was Action Research with Co-operative Inquiries in the form of search conferences. The study was initiated in February 2012 and completed in March 2013. The initial study participants consisted of the six members of the Protective Workshop Unit. They were appointed as co-researchers along with two additional service user representatives to form the Co-operative Inquiry Group (CIG).

The study included an initiation meeting in February 2012 and data construction at four search conferences held between July 2012 and February 2013. The findings of the study were presented to the SAFMH Directors in March 2013.

3.2 Research Design

Action Research (AR)[2] with co-operative inquiry (CI)[16,89] had been used successfully as the preferred study design by three studies (as described in Chapter 2) to develop new service delivery frameworks and implementation strategies. The form of co-operative inquiry used in this study was search conferences[21]. The application of AR with CI as the preferred methodology will be further explained.

As described by Reason[16,88], Action Research (AR) does away with the researcher-subject distinction and participants become co-researchers and co-subjects. Action Research consists of cycles of planning, action, observation, reflection and re-planning in an attempt to solve real situational problems in service delivery and practice by the persons in the situation working together to find solutions to the problems[90].

The AR process utilised is illustrated as a continuous progressive spiral as seen in Figure 3.1.

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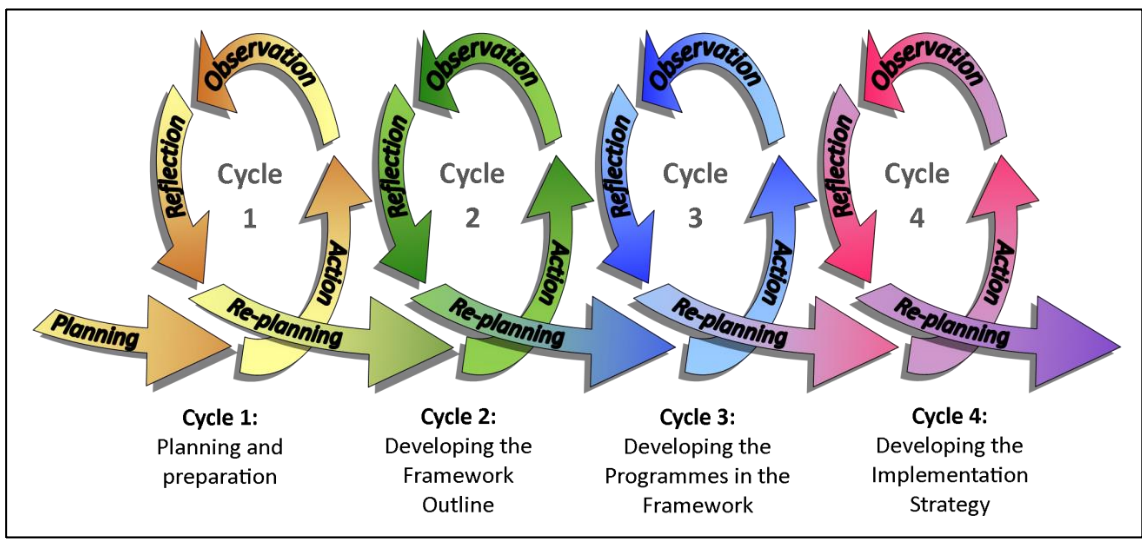

Figure 3.1 The AR Cycles in this study

This study went through four AR cycles between February 2012 and February 2013. The cycles were named by the researcher according to the outcome of the cycle as follows:

Cycle 1: Planning and preparation
Cycle 2: Developing the Framework Outline
Cycle 3: Developing the Programmes in the Framework
Cycle 4: Developing the Implementation Strategy

Although the study went through four AR cycles of planning, action, observation, reflection and re-planning, four search conferences that were conducted as part of the research process were not exactly aligned with the four AR cycles. Cycles 2 and 3 took place over three search conferences, while cycles 1 and 4 were completed within parts of search conferences. Due to the cyclic nature of the AR process, the reality of the study was not as predictable as indicated with the arrows in Figure 3.1. This is aligned to what Mendez describes (as cited by O'Brien[2]) as the messiness and non-linearity of AR. Table 3.1 provides the timeline and duration of the research meetings and illustrates the alignment of the research meetings with the participant groups and the AR Cycles.

Table 3.1 The alignment of research meetings, participant groups and AR Cycles

Research Meetings	Timeline	Duration	Participant Group	AR Cycles
Initiation Meeting	February 2012	2 days	PW Unit	Cycle 1
Search Conference 1	July 2012	4 days	CIG	Cycles 2
Search Conference 2	October 2012	3 days	CIG	Cycles 2 and 3
Search conference 3	November 2012	2 days	CIG	Cycles 2 and 3
Search Conference 4	February 2013	3 days	CIG	Cycles 3 and 4
Presentation to SAFMH Directors	March 2013	1 day	CIG	–

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Aligned to the description of Heron and Reason[83], co-operative inquiries in this study was used as a research tool and involved managers and service users of PWs in conducting research while moving through cycles of being part of the experience and reflecting on their experience and drawing from their expertise. During the co-operative inquiries, the participants as co-researchers designed and managed the project while their thinking and decision-making contributed to generating ideas on the implementation of the research process.

Search conferences were developed exclusively to suit the needs of the AR approach, as suggested by Trist[21], who describes a search conference as a meeting of relevant stakeholders under island conditions (away from everyday responsibilities) for two to five days to construct a picture for a desirable future for organisational settings. The aspects discussed at search conferences are named by Trist[21] as: Scanning the Issue, Desired Futures and Options for Change. The content is contributed entirely by the participants as co-researchers and all items listed and recorded on flip chart paper and displayed around the room. This study included four search conferences with duration of between two and four days.

Aligned to what O'Brien[2] describes, the participants understood the working and challenges of the PWs and acted as project designers and co-researchers of this study. Participants equally contributed to the creation of interpretive categories of analysis negotiated amongst the participants. As described by O'Brien, theory therefore informed practice and practice refined theory in a continuous transformation[2].

In this study, the co-operative inquiry group was made up of five PW managers, a SAFMH staff member and two service user representatives as described below.

The study leader was mandated by the CIG to communicate the progress made with the study to the SAFMH Executive Director.

3.3 Participants

Convenient sampling was used in this study. Since the aim and objectives of the study focussed on the transformation of the SAFMH PWs to get our house in order, all participants were related to the SAFMH and external participants (i.e. DSD) were not included. The participants in the study consisted of two groups, namely the SAFMH PW Unit and the Co-operative Inquiry Group (CIG) as described below. The researcher belonged to both participant groups and was appointed as the study leader by the CIG.

3.3.1 The SAFMH PW Unit

The SAFMH PW Unit consisted of five SAFMH PW managers (who volunteered to form this unit at the SAFMH Workshop for PWs held in February 2011 in Randburg) and a SAFMH staff member assigned to the unit by the SAFMH Director to form a link between the PW Unit and the SAFMH Office (refer to Table 3.2). All six members of this group

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became co-researchers in the CIG. The SAFMH PW Unit participated in Cycle 1 during the planning and preparation of this study.

3.3.2 The Co-operative Inquiry Group (CIG)

This second participant group, the Co-operative Inquiry Group (CIG), was made up of eight co-researchers: the six members of the SAFMH PW Unit (as described above) and two SAMHAM service user representatives (as described below). The CIG participated in Cycles 2, 3 and 4 and in the presentation to the SAFMH Directors at the end of the study.

Table 3.2 Participant information and background

	Code	Race and Gender	Age	Originating MH Society	Representing	Qualification/ Background	No of PWs	No of Service Users	PW Unit	CIG
1	CR1	White Female	43	Cape MH	PW Managers	Occupational Therapist	4	500	✓	✓
2	CR2	Indian Female	42	Durban & Coastal MH	PW Managers	Social Worker	9	700	✓	✓
3	CR3	Coloure d Male	51	PortElizabet h MH	PW Managers	Business	3	140	✓	✓
4	CR4	Black Male	46	North Gauteng MH	PW Managers	Project Manager	3	43	✓	✓
5	CR5	Black Male	28	Central Guateng	PW Managers	Social Worker	2	43	✓	✓
6	CR6	Black Female	54	SAFMH Office	SAFMH Office	Social Worker	–	–	✓	✓
7	CR7	Coloure d Female	38	Cape MH	Service Users with ID	Grade 10	–	–		✓
8	CR8	Black Male	28	Limpopo MH	Service Users with PD	Grade 12	–	–		✓

It should be noted that the five PW managers on the PW Unit and CIG managed 21 of the 31 SAFMH PWs with 1426 of the total 2409 service users in SAFMH PWs at the time of the study (refer to Table 3.2 above and Appendix A).

Since SAFMH has a policy to include service users in decision making about programmes and services offered, aligned with "Nothing about us without us"[58], it was agreed that the study would include two service user representatives assigned by SAMHAM to

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represent mental health care users on the CIG. Since this study required service user input, but was not primarily a study of service user opinions, only two service users were included to represent service users. The members of SAMHAM decided to include a person with psychiatric disability since some of the PWs provide services to both service user groups and the outcome of the study could potentially also influence future service provision to persons with PD. Both service users were assigned a familiar CIG member to take on the role of their supporter (as described later).

The second person assigned by SAMHAM to the CIG to represent the service users with mental disabilities (including ID) was a 28-year-old male with psychiatric disability from Limpopo Mental Health who is a service user of the Limpopo Self-help Group, an income generating farming project in the rural area of Tzaneen in Limpopo. He had completed Grade 12 and was unemployed at the time. He had 2 years' experience of self-advocacy as part of his involvement with SAMHAM. During participation in the CIG, he needed support to manage his anxiety levels and assist with translation since English was his second language. The SAFMH staff member acted as his supporter and interpreter on the CIG since she was fluent in his first language and a qualified social worker that has experience in supporting persons with psychiatric disability.

The person with ID assigned to the CIG by SAMHAM was from Cape Mental Health (the same organisation where the researcher was employed). She was a 38-year-old female with mild ID with a Grade 10 educational level with basic reading and writing skills. At the time of the study she had four years' experience of self-advocacy and representing persons with ID as the Chairperson of the Training Workshops Unlimited (TWU) Trainee Council, a CMH Board Member and a SAFMH Board and Executive Committee Member. This person should therefore not be regarded as vulnerable within the context of this study.

As one of the service users expressed the need for additional support during the search conferences to optimise her participation in the search conference discussions, a designated supporter was appointed. The role of the supporter to the person with ID included support and reassurance of this service user to manage anxiety levels during discussions and interaction with co-researchers and staff, to ensure the service user understood discussions, context and her role on the CIG, to assist the service user to formulate responses and input, and to advocate for accommodation of her special needs. These special needs included more regular breaks (due to short attention span), use of pictures and visual presentation of topics (due to a lower literacy level) and to allow whispering between the service user and supporter during discussions to ensure understanding of the discussions. Initially one of the co-researchers fulfilled this role, but at the third search conference a designated supporter was brought in as an additional resource. This was done following an incident where the service user with ID became emotional in a session following a comment from another co-researcher that the service users should be more vocal with their input. The service user explained that

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it was difficult for her to keep up with the pace of the discussions without a designated supporter who could clarify terms and rephrase difficult words in easier language for her. Although the support she received from the other co-researchers was reassuring, it was not sufficient to optimise her participation in the search conference discussions. A designated and experienced supporter of her choice and with whom she was familiar was therefore appointed for her as from the third search conference. This supporter was also from CMH and supported this service user at various forums and meetings on an organisational, provincial and national level prior to this study. She was trained as part of the CMH supporter training programme and was part of a Cape Mental Health team of supporters who won a Hamlet Foundation Award for their role in service user advocacy in 2012.

3.3.3 Participants who left the study

Two members of the CIG (a PW Unit member (CR 5) and the SAMHAM service user representative with PD (CR8)) chose to leave the CIG group after the second search conference due to personal and work-related reasons. The CIG regarded the SAFMH PW managers to be sufficiently represented and decided not to include another PW Manager as a replacement. The choice to assign a replacement service user representative to join the CIG was given to SAMHAM. A replacement was assigned, but the person could unfortunately not join the remaining search conferences due to personal reasons. He therefore never became a co-researcher. He was, however, invited and attended the presentation to the SAFMH Directors.

3.4 Research Context

This study was commissioned and funded by the SAFMH. The SAFMH Board instructed the PW Unit to undertake the study and requested a presentation of the findings to the SAFMH Board Executive and Directors of the member mental health societies in March 2013.

The SAFMH structure (as described in Chapter 1, page 1) had an influence on the study as described below.

Firstly, the 31 PWs operated by the different mental health societies (refer to Appendix A) developed and operate independently without any central coordination or monitoring of programmes, deliverables or standards by SAFMH. The difference in service provision was clearly evident in the presentations done at the PW managers Workshop in February 2011. As a result the participating PW managers and service users had different frame of references relating to PWs. The researcher therefore had to ensure effective sharing the different PW models, experiences and different understanding of the needs of persons with ID. It was further important to clarify and

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confirm terms, concepts and guiding principles to align the frame of reference of all before the development of the SAFMH framework and implementation strategy.

Secondly, the PW managers and service users participating in the study were not SAFMH employees and SAFMH therefore had no line management authority over them. The five participating PW managers were employees of five different independent mental health societies in four different South African provinces. The two service user participants were assigned by SAMHAM and participated with the agreement of their two mental health societies. The study plan therefore had to include terms of collaboration that was agreed by all to ensure effective working relationships.

Thirdly, most of the participants did not know one another before the study. The managers met at the PW managers Workshop in February 2011 when they volunteered to steer the SAFMH PW Unit (as described in Chapter 1, page 1). They met again only a year later in February 2012 at the study initiation meeting. The SAFMH staff member (also the SAMHAM Co-ordinator) knew the two service user representatives and the researcher knew the service user with ID (since they were both from Cape Mental Health). This meant that most of the co-researchers entered the study with very little knowledge of one another and their respective PWs. The researcher therefore had to allocate time for introductions and ensure that the participants understood group dynamics (as described later in this chapter). This was important for building trust amongst the CIG members aligned with the quality criteria for co-operative inquiry identified by Meulenberg-Buskins[91].

3.5 Data collection

The data collection methods used for this study were qualitative. The researcher facilitated a group discussion with the CIG on what would be regarded as data sources. It was agreed that all search conference sessions would be recorded digitally and transcribed after the search conferences. It was agreed that other data sources would include the flip chart sheets created as part of the process, the completed reflection diaries, the study journal and diary, and data from any data collection tools that were developed as part of the study including research progress reports, written communication and transcriptions of voice recordings of the search conference sessions and meetings. It was acknowledged that the need for data collection tools would emerge from the research process and the tools would be developed as needed. It was agreed that the original flip chart sheets would remain with the study administrator, but that the researcher would take photographs of all flip file pages and use these as source documents.

3.5.1 Data collection strategies

Data collection strategies included:

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- Data construction at search conferences (co-operative inquiries), meetings and presentations as evident in flip chart pages, audio recordings, transcriptions and spread sheets.
- Keeping research journal and notebooks, reflection diaries kept by all CIG members and a research inquiry audit with thick descriptions of the process, findings, reflection cycle notes and planning logs to ensure triangulation of data provided by different CIG members at different stages of the research process. The thick descriptions included detailed information on the setting, the topics under discussion, the behaviour and interaction between the CIG members and the consensus reached.

3.5.2 Data construction techniques

The following techniques were used in data construction in this study and will be described later in this chapter in the detailed description of the different phases of the study:

- **Brainstorming**: a group discussion where the free flow of ideas are used to come up with as many as possible thoughts related to the set desired outcome in a set period of time[92].
- **Negotiated consensus**: a resolution as result of a group decision-making process resulting in a general agreement acceptable to and supported by all participants that comes about through discussions and negotiation; according to Coglianese[93] negotiated consensus represents group solidarity of belief or sentiment.

3.6 The four AR Cycles and Steps

Each of the four AR Cycles will be described in terms of steps towards meeting the main outcome of the cycle. Figure 3.2 on page 39 provides an overview of the steps for each of the four AR Cycles.

The four Cycles of this study will be described in detail.

3.6.1 CYCLE 1: PLANNING, APPROVAL AND PREPARATION

As can be seen from Figure 3.2, Cycle 1 consisted of 2 steps, namely:

Step 1: Research initiation, planning and approval
Step 2: Transforming from a PW Unit into a co-operative inquiry group (CIG)

The steps are described in detail below.

STEP 1: Research initiation, planning and approval

The study was initiated at the first 2-day meeting of the PW Unit (5 PW Managers and a SAFMH staff member) in February 2012 in Randburg. This step included confirmation of

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the study brief and mandate, deciding on the methodology and inclusion into the study plan. The study plan and budget was drafted to obtain funding approval from the SAFMH.

Confirming the SAFMH brief and mandate

At this meeting the SAFMH staff member in the unit started with a PowerPoint Presentation on the mandate and brief for the study provided by SAFMH to the PW Unit to develop a framework of best practice and implementation strategy to transform SAFMH PWs. The findings were to be presented for approval and adoption by the SAFMH Directors by March 2013. SAFMH undertook to secure funding for the study and the PW Unit was asked to submit a study plan and budget to the SAFMH Directors for approval by the end of March 2012.

The presentation was followed by a group discussion and an agreement by the unit members to accept the mandate and commit to the study. The drafting of the study plan started with a group discussion facilitated by the researcher according to the questions of “what” would be done, “how” it would be done, “who” would do it, “when” it would be done and “where” it would be done. The “what” question was answered by refining the research question and study aim. The study leader facilitated this by asking leading questions and rephrasing the responses into a research question and study aim. The study aim was recorded on flip chart paper and displayed on the wall as reference during the drafting of the plan.

Deciding on the methodology

The methodology was agreed upon during a group discussion through negotiated consensus on four aspects including the study design, the use of search conferences, ensuring reflective practice and data collection. These 4 aspects are discussed below in more detail.

Study design

It was agreed that the methodology selected should allow for a negotiated consensus by all PW Unit members and service user representatives on a new framework that would be suitable for all SAFMH PWs. It was agreed that a participatory study design was therefore needed and led to the selection of AR with CI as the preferred study design. The researcher prepared a PowerPoint presentation on AR with CI and presented it at the next meeting to ensure all members were familiarised with the methodology. It was agreed to keep a research journal and notebooks to track the research process. In addition the researcher kept a diary and a research audit with thick descriptions of the process as well as a planning log.

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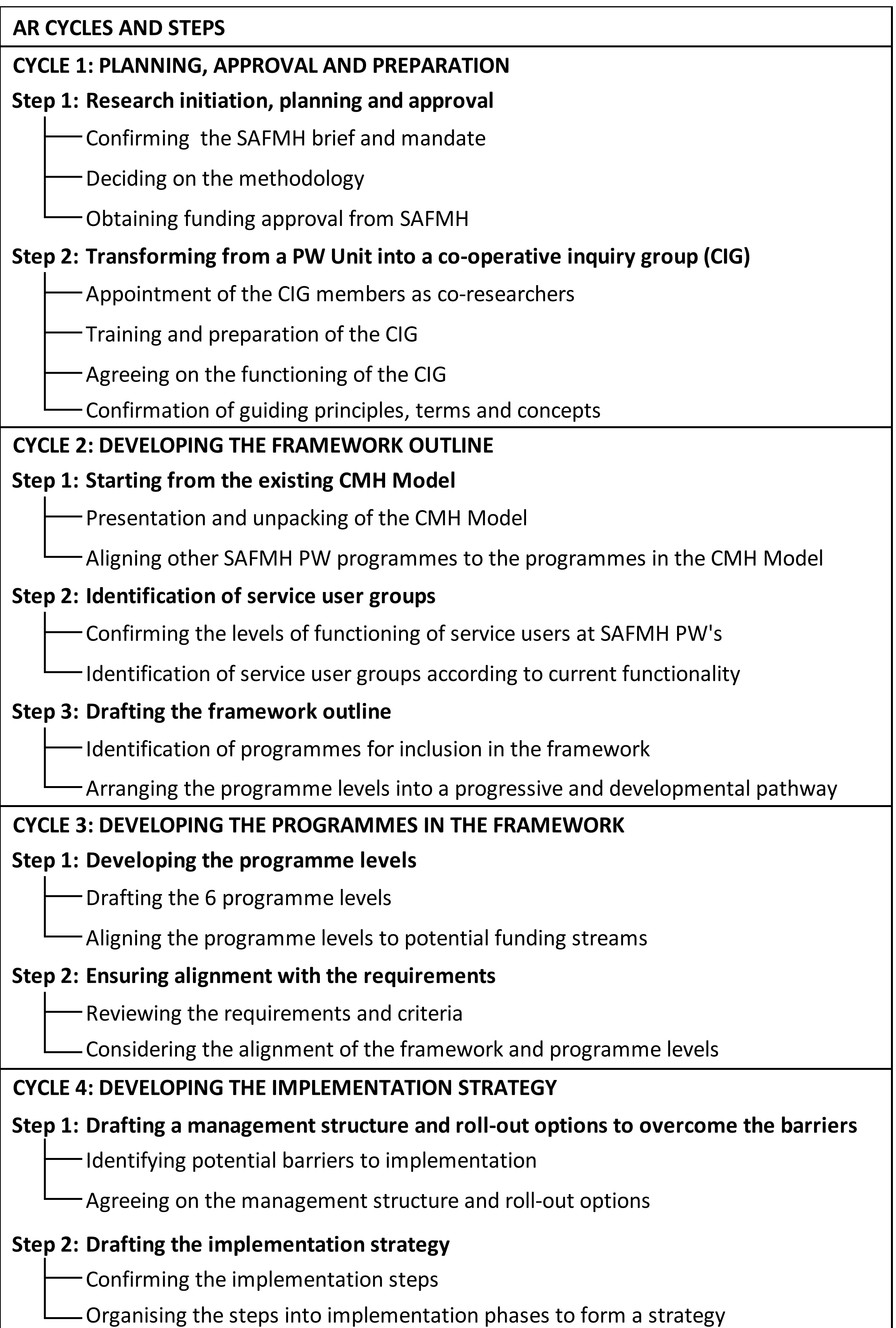

Figure 3.2 Overview of the AR Cycles and Steps

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Search Conferences

It was agreed that it would be best to develop the framework and implementation strategy at meetings held over a few days, away from the members' everyday commitments so that they could focus on the task at hand. It was decided to schedule 4 search conferences between July 2012 and February 2013 for this purpose. It was agreed to rotate the search conferences between the locations of the CIG members to allow for visits to the different PWs and potential focus group interviews with the managers of PWs in that region as envisaged data collection strategies.

It was agreed that the search conferences could vary in duration depending on the availability of the co-researchers. At the end of each search conference the plan for the next conference would be outlined and the interim activities listed and assigned to specific CIG members. The CIG met with the SAFMH Executive Director on the last day of the initiation meeting and during search conferences 2 and 3. The purpose of these meetings was to discuss the progress made with the study, to confirm that expenditure was still aligned with the approved budget and to discuss any emerging matters related to the study. Such emerging matters mostly centred around concerns relating to logistics, such as catering (a request from the CIG to scale down on the lunch provided to save costs) and transport difficulties (including late communication regarding flight / shuttle details and long waiting periods at airports). A progress report was drafted and submitted to the SAFMH Executive Director following each search conference.

The CIG decided to keep the structure of the search conferences similar throughout the study. The daily programme was agreed upon as illustrated in Table 3.3.

Table 3.3 Search conference daily programme

Time	Activity
08:00 – 09:00	Sharing of individual reflections of the previous day with CIG and group discussion
09:00 – 11:00	Session 1
11:00 – 11:15	Tea
11:15 – 13:00	Session 2
13:00 – 13:30	Lunch
13:30 – 15:30	Session 3
15:30 – 16:00	Written recording of individual reflections of the day
16:00	Closure

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During most of the search conferences Session 3 fell away on the last day to accommodate travel arrangements or to allow for a meeting with the SAFMH National Director.

The sessions of all the search conferences were digitally audio recorded and transcribed to confirm the discussions, decisions, agreements and consensus reached. The CIG agreed at a project meeting for the transcriptions to be outsourced and tasked the study leader to obtain the services of a transcriber. The study leader confirmed the accuracy of the first transcription by reading the transcript while listening to the audio recording. Similar accuracy spot checks were done with all the other transcriptions.

It was important to align the scheduling of the search conferences with the envisaged outcomes, the availability of the co-researchers and the SAFMH calendar of events. The period for the study was already determined by the SAFMH as between February 2012 and March 2013. The four search conferences were plotted on flip chart paper with tentative dates and outcomes for each search conference. It was agreed to confirm the exact dates for each search conference at the end of the previous search conference.

Reflective practice

Due to the requirement for reflective practice through regular individual and group reflection as part of the AR process throughout the different cycles and stages, it was decided to use a daily reflection diary during search conferences. The researcher was tasked to draft a reflection diary template for the CIG. The template had to be suitable for use by all the CIG members including a service user with ID. The different aspects for reflection on the template were therefore indicated by a short question with a clipart picture of a smiley face emoticon[94] associated with the question (refer to Figure 3.3).

The clipart picture assisted the CIG members, and especially the service user with ID, to recall the questions and to make the Reflection Diary user-friendly.

The draft Reflection Diary form was explained to the CIG on the first day of the first search conference. All CIG members indicated that they understood the use of the form and agreed to complete a Reflection Diary reflecting on the proceedings of that day and gave feedback on their reflections in the first session on the next morning. After the CIG members had given feedback to the group the next morning, a discussion was facilitated by the researcher to evaluate the form. All CIG members agreed that it worked well and it was adopted as the tool to be used for individual reflection at the end of each day of the search conferences.

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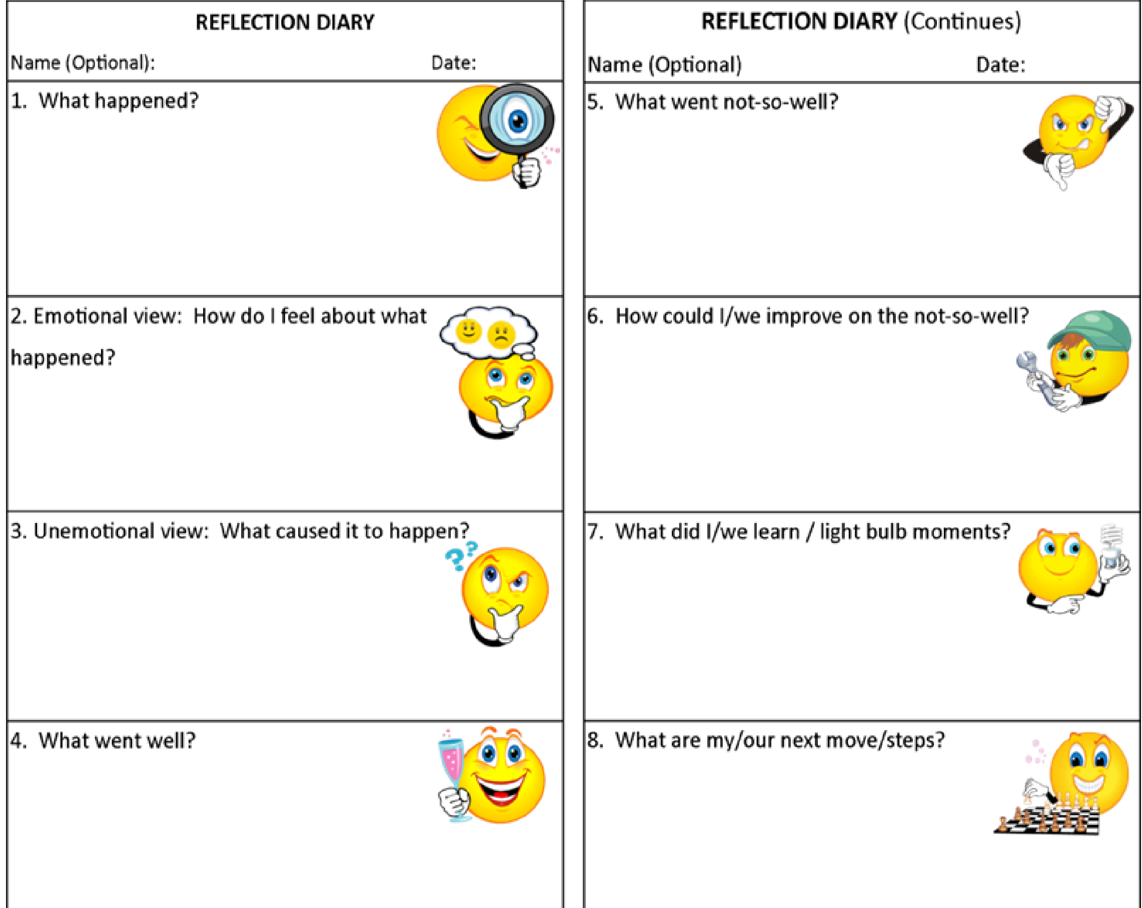
REFLECTION DIARY

Name (Optional):	Date:
1. What happened?	
2. Emotional view: How do I feel about what happened?	
3. Unemotional view: What caused it to happen?	
4. What went well?	

REFLECTION DIARY (Continues)

Name (Optional)	Date:
5. What went not-so-well?	
6. How could I/we improve on the not-so-well?	
7. What did I/we learn / light bulb moments?	
8. What are my/our next move/steps?	

Figure 3.3 The Reflection Diary form template

It was agreed that members could decide on the extent and the content of what they shared in the feedback session at the beginning of the following day of the search conference and that recording identifying details on the form was optional. It was further agreed that all the Reflection Diary forms would be collated and kept in the research study file. It was agreed that the reflection feedback sessions would be recorded and transcribed to form part of the content analysis. The researcher collected the Reflection Diary forms after each reflection session and kept them in a file.

It was agreed that the researcher would facilitate the reflection feedback sessions by asking for a volunteer from the CIG group to give feedback from the individual reflections done at the end of the previous day recorded in the Reflection Diaries. The other CIG members would then follow on a voluntary basis and share their reflections with the group.

Obtaining funding approval from SAFMH

Funding for the study was dependent on the approval of the study plan and budget by the SAFMH Directors. Following the drafting of the study plan (as described above) the PW Unit drafted a study budget and made provision for costs including travelling (flights and airport shuttles for out-of-province participants and private mileage claims for

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Gauteng participants), accommodation (for all participants to stay as a group during search conferences and meetings), venue and catering (for search conferences), and professional fees and per diems. It was agreed to include a professional fee in the budget based on a daily rate to be paid to the respective mental health societies for releasing the CIG members for this study. This was necessary to enable the employers to acquire additional capacity as needed to ensure uninterrupted service delivery at the PWs from which the CIG members originated. The two service users were paid an allowance (per diem) per search conference that they attended to cover additional costs they might incur as part of their participation in this study.

The first draft study plan and budget were presented to the SAFMH Executive Director at a meeting at the end of the Study Initiation Meeting. Recommendations from that meeting were included in the study plan that was submitted to the SAFMH Directors in March 2012. The study plan was approved, subject to the requirement for all search conferences to be held at the SAFMH Offices in Randburg and not rotated between CIG members' locations.

The CIG was not satisfied with the decision that all search conferences should be held in Randburg and therefore held a telephone conference to discuss the issue. It was felt that rotation of the search conferences was an important factor for the inclusion of the other SAFMH PW managers in the study. The PW Unit therefore tasked the researcher to provide further motivation to the SAFMH Directors in the form of a letter and two budgets outlining the cost for each option (rotating and not rotating the search conferences). After careful consideration of the researcher's motivation letter and the two budgets options, the SAFMH Directors ruled that all the search conferences were to be held at the SAFMH Offices in Randburg. It was recommended that the CIG find creative solutions to get the input from the SAFMH PW managers since face-to-face data collection including other participants would not be possible within the limitations of the funding. The co-researchers therefore all travelled to Randburg for the search conferences and stayed as a group in a nearby lodge for the duration of the search conferences.

The SAFMH Directors approved the study to be done as part of the researcher's Master's Degree in Occupational Therapy.

STEP 2: Transforming from a PW Unit into a co-operative inquiry group (CIG)

According to Meulenberg-Buskens's[91] quality criteria for co-operative inquiries, all members of the CIG group were aligned to the purpose of the research, the ownership of the inquiry process were transferred from the researcher to the group and collaborative group dynamics. It was therefore important to spend time to transform into a functional CIG before the study was undertaken. This included the appointment of the CIG Members as co-researchers, the training and preparation of the CIG, agreement on the functioning of the CIG and confirmation of terms and concepts.

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Appointment of the CIG Members as co-researchers

The identified CIG members (refer to Table 3.2) were appointed as co-researchers in the study before the first search conference held in July 2012 and they were all required to sign the Investigator's Declaration required by the Health Research Ethics Committee of the Faculty of Medicine and Health Sciences, Stellenbosch University (ref. S12/05/143) (sample attached as Appendix C). The researcher forwarded the declaration form to the participants via e-mail explaining the purpose and requesting them to complete and return with a copy of their curriculum vitae.

Training and preparation of the CIG

Since all the members of the CIG were not part of the Study Initiation Meeting in February 2012, the researcher started the first search conference with a revision of the aim of the study, the mandate received from SAFMH and the approved study budget to ensure a common purpose and understanding amongst the CIG members. This was done to ensure that all CIG members were aligned to the purpose of the study.

The researcher was also tasked to train and prepare the CIG to undertake the study and to ensure understanding and optimal participation by all. This training was done through a PowerPoint presentation of the research protocol including the ethical considerations, the findings of the preliminary literature review and the methodology of AR and CI. It was explained how innovation could be achieved through cycles of planning, drafting, reflecting and re-planning. The researcher further facilitated training sessions on teamwork, group dynamics and conflict resolution.

After the training the members confirmed understanding of the methodology and concepts, but some co-researchers expressed doubt that the group's discussions would lead to innovation and data construction. The researcher reassured the CIG members that a level of fear of the unknown was normal at this stage of the research and that they would gain confidence in the process as they saw the AR process working and became more familiar with it. This principle is described by O'Brien[2] under the AR principle of risk that creates "psychic" fears amongst co-researchers due to the risk from ego-stemming during open discussions of one's interpretations, ideas and judgments. The researcher reassured the CIG members that they were the best suited persons to be the co-researchers in this study to develop this framework and strategy since they knew the SAFMH PWs, the service users' needs and the current concerns the best. The CIG members re-committed themselves to the study and the outcomes.

Agreeing on the functioning of the CIG

According to Meulenberg-Buskens's[91] quality criteria of transferring ownership of the inquiry process, ensuring democratic and collaborative group dynamics and facilitation, and to develop trust within the group, a discussion was held to agree on the functioning

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of the CIG. The three aspects that were agreed upon relate to the terms of collaboration, facilitation during search conferences and confirmation of the roles and responsibilities of the CIG members – and these are discussed below in more detail.

The following specific roles and duties were decided on:

The study leader: It was decided that the researcher would act as study leader and facilitate the AR Cycles and stages to ensure that all CIG members participated equally in discussions and agreements to reach the study aim. This is aligned to what O'Brien[2] stated as the main responsibility of the researcher's role: viz. to implement the AR method in a manner to produce a mutually agreeable outcome for all participants and nurturing the co-researchers to the point where they can take responsibility for the process. The researcher took on many different roles at different stages of the process (including those of planner, leader, catalyser, facilitator, teacher, designer, listener, observer, synthesizer and reporter) to accomplish that outcome[2].

The CIG Administrator: It was agreed that the SAFMH Staff Member on the PW Unit would act as CIG Administrator and take responsibility for all logistical arrangements (with the SAFMH Administration Department) and other administrative duties relating to the study.

Other roles and responsibilities: Other roles that were accepted by individual CIG members (including the service user representatives) were those of scribe, timekeeper, interviewer and co-facilitator at different stages in the study.

Terms of collaboration

The CIG discussed and agreed on terms of collaboration as (1) joint ownership, (2) confirmation that participation in the study was voluntary, (3) that all opinions would be respected, (4) that the findings would respect confidentiality and not identify any co-researcher for input given and (5) that disagreement will not be seen as negative. The CIG further agreed that innovation does not mean merging a few existing programmes into a framework, but through looking at and reflecting on the existing frameworks to shape new ways of thinking to address the challenges faced by the SAFMH PWs and service users.

Facilitation during search conferences

In addition to the decision that the study leader would be the main facilitator of the discussions and different cycles and stages in the AR process, the CIG agreed to ensure that no single member dominated the discussions or the process. This was ensured through a decision to jointly draft the daily programme and by allocating tasks to different group members including that of timekeeping, recording the key points on flip

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chart sheets, transcription of the flip chart pages and drafting the reports of the search conferences.

Confirmation of the guiding principles, terms and concepts

Before the development of the framework could be done, the CIG agreed to discuss and confirm the guiding principles for the development of the new framework. This is aligned to one of the ethical considerations for AR identified by Winter[95]. In addition discussions and sharing of current practice examples and case studies informed the identified principles. The principles identified related to the aspects of the stigma associated with PWs, the rights and status of the service users with ID and increased sustainability of PWs and will be discussed in the next chapter as part of the findings.

Since the CIG members were from five different SAFMH mental health societies they used different terms to refer to the same concept, for example referring to the service users at PWs as trainees, beneficiaries, clients or participants. It was important to ensure a common understanding of terms and concepts relating to the study. Each conflicting term was identified and discussed and the preferred term for use during the study was agreed on. A list of terms is included under definitions in Chapter 1.

Following the planning and preparation done in Cycle 1 (as presented in Figure 3.3), the CIG was ready to engage with Cycle 2: The development of the framework outline.

3.6.2 CYCLE 2: DEVELOPING THE FRAMEWORK OUTLINE

Cycle 2 consisted of 3 steps, namely:

Step 1: Using the CMH Model as a starting point

Step 2: Identification of the service user groups

Step 3: Drafting the Framework Outline

The 3 steps will be described in detail below.

STEP 1: Starting from the existing CMH Model

The PW model developed and implemented by Cape Mental Health (CMH) in the Western Cape was identified by the SAFMH Directors as an innovative programme that could inform the development of the new SAFMH Framework. This model was developed by the researcher and the TWU senior management team in 2000. The researcher and Training Workshops Unlimited have won numerous awards and the TWU model is regarded as a best practice model by the SAFMH and the Department of Social Development (DSD[6]).

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The SAFMH Directors indicated that the CMH model could not be adopted as the SAFMH Framework, since it had only been implemented in Cape Town at that time and might not meet the needs of the service users at all the SAFMH PWs in urban, peri-urban and rural areas. The SAFMH Directors therefore instructed the CIG to use the CMH PW Model as a starting point in this study.

Presentation and unpacking of the CMH Model

Before the new framework could be developed, it was important to unpack the CMH model[34] for all the CIG members to understand the different training programmes that form the training and career path in the model, the functional abilities of the service users who benefit from the different programmes and how service users can progress from one level to the next in the pathway.

To achieve this understanding, the CMH PW Manager (the researcher) presented the CMH PW Model to the CIG at the first search conference over two sessions through a combination of PowerPoint Presentations, flip chart drawings, discussions, demonstrations of training materials and assessments and sharing of management strategies in the transformation of the CMH PWs.

Figure 3.4 gives an overview of the CMH PW Model[34].

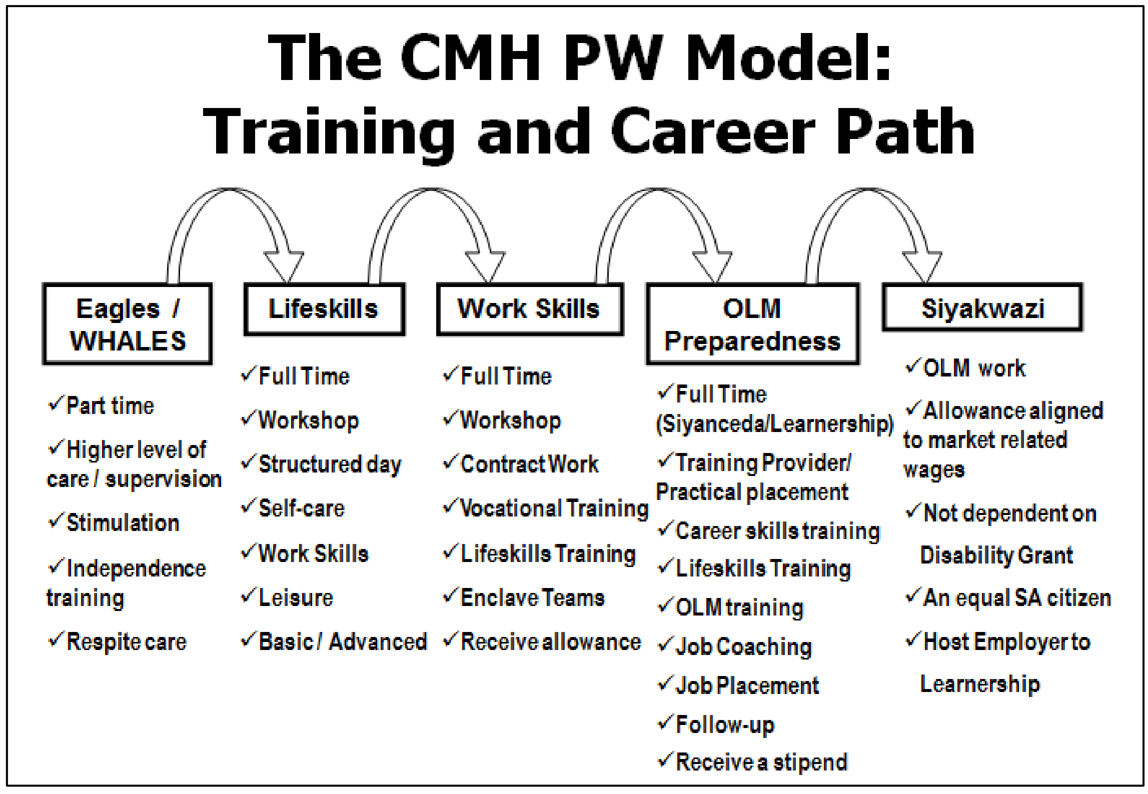

Figure 3.4 The Cape Mental Health Protective Workshop Model[34]

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Following the presentations and information sharing, the CIG unpacked the model by separating and discussing each programme individually in terms of the service user groups according to functional abilities and by provisionally identifying the components and programmes considered to be suitable for inclusion in the SAFMH Framework of best practice for PWs. As an outcome of this process, six service user groups were identified as well as programmes in the CMH PW Model suitable for inclusion in the new SAFMH framework. This will be discussed as part of the findings in Chapter 4.

Aligning other SAFMH PW programmes to the programmes in the CMH Model

Following the presentation and unpacking of the CMH Model, the other 4 PW managers and one of the service users (the other service user was also from CMH) representative on the CIG were asked by the researcher to share the programmes and models implemented at their respected PWs. This was done in a single 2-hour session through verbal presentations. The group was seated at tables arranged in a U-shape format to allow for eye contact. The flip chart was situated at the open end of the table formation and could be used if preferred. The researcher assumed the role of facilitator, listener and clarifier in this session.

Each presentation was followed by random questions posed by the CIG members for clarity and based on the information presented. The other four PW managers and the two service users on the CIG represented a sample of SAFMH PW located in the urban, peri-urban and rural areas of Durban and surrounds, Port-Elizabeth, a township north of Pretoria, townships in the Johannesburg area and a rural town in the Limpopo Province.

Due to the lack of uniformity amongst the different models used at SAFMH PWs and difficulty in visualising the models presented by the CIG members, the researcher asked the CIG members who presented their models to align and plot their programmes, presented on a flip chart sheet to the programmes in the CMH model based on similar outcomes and service user functionality. This was done to ensure that the CIG had a common understanding of services provided by the different programmes and what lay outside of their frame of reference at the time. The other CIG members assisted with this process, based on their understanding of what was presented.

This first step of Cycle 2 was very important to form a basis of understanding for the drafting of the first outline for the new envisaged framework in step 3 described later.

STEP 2: Identification of the service user groups

During this step the researcher acted as facilitator and synthesizer. It was agreed to first identify the level of functioning of all the service users at SAFMH PWs and then classify them according to functionality into groups for effective service delivery.

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Confirming the levels of functioning of service users at SAFMH PWs

As part of the presentations by the CIG members on services offered at their PWs, they provided information on the functionality of their service users. This was found to be similar to the information on service users at all other SAFMH PWs that was shared during the workshop in February 2011 when the notes and presentations were reviewed. This information assisted the CIG to list the average functional levels of the SAFMH service users on flip chart sheets in terms of self-care, life skills, work skills, ability to understand and follow instructions, level of independence and the level of support and supervision needed.

Identification of 6 service user groups based on current level of functioning

After the functionality and level of support and supervision needed had been listed, the CIG identified 6 service user groups according to functionality, level of independence, assistance and support needed for activity participation, and level of supervision needed for safety and to meet quality requirements. This will be discussed in detail in Chapter 4.

Once the service user groups were identified, the CIG could start with the drafting of the framework outline to ensure service delivery options for all service user groups.

STEP 3: Drafting the Framework Outline

To agree on a first draft for the Framework Outline, the CIG agreed first to identify the programmes for inclusion in the framework and then arrange the programmes in a progressive and developmental pathway.

During this step the researcher assumed the role of synthesizer, catalyser and designer by, together with the CIG, drawing together the parts of the CMH Model and the models presented by the other CIG members identified for inclusion and drafting them into a new framework structure. The activities are described in detail below.

Identification of programmes for inclusion in the framework

The first drafting of the outline for the new framework was done through discussions and agreement through negotiated consensus on which programmes from the CMH Model and aligned other SAFMH PWs programmes (following step 1) should be included in the framework. The agreed programmes and components were first listed on a flip chart sheet and given a generic name, based on the service rendered or the training focus of the programme.

The programmes were then matched to one of the 6 identified service user target groups based on the level of functioning of the group and the service needs and level of support required for participation in the programme. This activity was done to ensure that all service users are accommodated in a programme level in the new framework

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that would make provision for their service needs and provide the level of support required.

Arranging the programme levels into a progressive and developmental pathway

The programme levels were then arranged in sequence, starting with the programme for the lowest functioning service user group and ending with the programme for the highest functioning group. This resulted in a progressive and developmental pathway according to the functionality of the service user groups and the training outcomes of the programmes aligned to the CMH Model presented. The outline of the pathway was drawn and redrawn on Flip Chart sheets until consensus was reached. The outline is provided here to provide clarity, but will be discussed in the next chapter as part of the findings.

The CIG agreed on 6 programme levels and gave the programmes the generic names of Higher Care, Life skills, Work Skills, Bridge to the OLM, Supported Employment and Supported Self-Employment as illustrated in Figure 3.5 designed by the CIG and used in the concept document and presentation on the newly developed SAFMH framework of best practice to the SAFMH Directors.

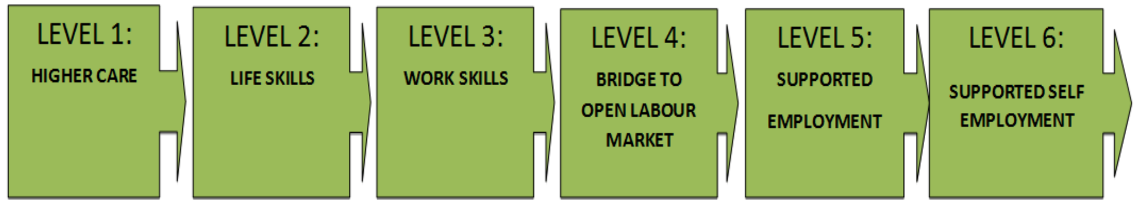

Figure 3.5 The developed SAFMH Framework of Best Practice Outline[96]

It was agreed that mental health societies would be able to choose which programme levels they would offer according to their organisational capacity and the functional abilities of their service users.

3.6.3 CYCLE 3: DEVELOPING THE PROGRAMMES IN THE FRAMEWORK

Owing to the limited time that the CIG had available during search conferences, Cycles 2 and 3 overlapped between July 2012 and November 2012. The CIG started with the drafting of the programme levels of the programmes aligned with the functionality and service needs of service user groups represented at all the SAFMH PWs (as reported during a SAFMH PW managers' Workshop held in February 2011). Programme Levels 2 and 3 were therefore drafted before the finalisation of the Framework Outline at the end of Cycle 2.

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STEP 1: Developing the 6 programme levels

For the development and drafting of the programme levels (refer to Figure 3.5 and Appendix F), the CIG first agreed upon the components to be developed for each programme level to ensure uniformity across the 6 levels. The CIG focussed on one programme level at a time and ensured that all the identified components were drafted before moving on to another programme level.

Before drafting the different programme levels, the GIC agreed through discussion and by negotiating consensus on the different components to be developed for each level as part of this study. It was agreed that the scope of this study did not allow for the development of the training materials for each programme level and that the focus should rather be on developing a framework for each of the programme levels. It was decided therefore to draft the following components for each programme level:

- the purpose
- the envisaged outcomes
- the admission criteria
- defining the service user target group
- the daily routine
- the outline of the training curriculum and
- staffing needs and ratios

The CIG agreed to decide on the ideal staff-to-service-user ratio for each programme level based on their experience and to make recommendations on existing training materials and assessment tools that could be considered for each programme level. Once agreed, the researcher listed the different aspects to be drafted for each programme on a flip chart sheet and displayed it on the wall next to the flip chart stand to keep the discussions focussed.

The agreement on the content for each of the components for the 6 programme levels was recorded once consensus had been reached through discussions and negotiation. The discussions allowed for debates and all members of the CIG had the opportunity to agree or disagree with one another and to ask for clarification or rephrasing. During this stage the researcher took on the role of facilitator and synthesizer (putting together the different inputs from the CIG and identifying where each part fits into the framework outline and within the aspects of the respective programme level being drafted at the time).

The researcher also took on the role of educator and presented additional information as a way of providing background information to equip those CIG members with less experience in a specific level with information to empower them to take part in the drafting thereof. The following was presented:

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- information relevant to the development of the programme levels, for example information on skills development including the Skills Development Act and the Sector Education and Training Authorities (SETAs)
- the process of securing funding for hosting learnerships and skills programmes for persons with ID.

Aligning the programme levels to funding streams

Following the drafting of the six programme levels, the researcher facilitated a session to align the different programme levels to potential funding streams in order to fulfil the requirement of the SAFMH Directors to include a strategy for longer-term sustainability of the programmes. This was done by aligning the focus of each of the programme levels (i.e. care, skills development, employment) with potential funding streams based on the past experience of the CIG members. The potential funders identified for each programme level were listed on a flip chart sheet that was displayed on the wall of the conference room for the remainder of that search conference. Additional potential funders and funding streams were added to the list as they came up in subsequent discussions.

STEP 2: Ensuring alignment with the requirements

In order to ensure alignment of the newly developed framework to the requirements set by SAFMH, the CIG first reviewed the requirements and drafted criteria for alignment. The CIG then considered the alignment of each of the 6 programme levels and the framework against each of the criteria.

Reviewing the requirements and criteria

To set the criteria for evaluation of the programme levels and framework, the CIG reviewed the guiding principles agreed upon in Cycle 1 (refer to page 46) and the SAFMH mandate (refer to page 39).

The criteria identified were that the programme levels and framework should:

- represent best practice for service delivery to adults with ID based on the findings of the preliminary literature review
- should provide for the needs of all adults with ID ranging from mild, moderate, severe and profound ID
- should promote the rights of persons with disabilities as reflected in the United Nations Declaration on the Rights of Persons with Disabilities (UNCRPD)
- should have a developmental focus and allow for progression according to the service users' abilities and at their own pace

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- should be attractive to funders and have the potential to be sustainable in the longer term
- should be aligned to the requirements set out in the Department of Social Development (DSD) Policy on PWs to continue to qualify for DSD subsidy

The researcher assumed the role of educator and reviewed the DSD requirements, the SAFMH mandate to the CIG, the rights of persons with ID and the identified service user groups to be provided for.

Considering the alignment of the framework and programme levels

For the discussions to determine whether the new programme levels and framework meet the criteria listed above, the flip chart pages (with the information pertaining to the different programme levels) were displayed on the walls to be visible to all CIG members. For each criterion, the CIG discussed how, to what extent and in which programme level(s) the criterion was adhered to in the new framework. The researcher pointed to the writing on the relevant flip chart pages as the CIG members identified aspects of the new framework that fulfilled the criterion under discussion. The CIG concluded that the newly developed programmes and framework met all the criteria and that no further adjustments were necessary.

At the end of this stage it was agreed that the CIG was ready to proceed to Cycle 4 with the outcome of drafting the implementation strategy.

3.6.4 CYCLE 4: DEVELOPING THE IMPLEMENTATION STRATEGY

The need for an implementation strategy was evident from the feedback received from CIG members and other SAFMH PW managers (during the PW managers' Workshop in February 2011) on their inability to initiate transformation as required by DSD. The first step in the drafting of the implementation strategy therefore was to agree on the barriers and the preferred management structure and roll-out options to overcome the barriers. The CIG then developed the implementation strategy by first identifying all the steps to be included in the strategy before organising the steps into nine chronological phases that could guide implementation.

STEP 1: Drafting a management structure and roll-out options to overcome barriers

Identifying potential barriers to implementation

Throughout the discussions during search conference sessions the CIG identified barriers for implementation that the implementation strategy would have to overcome. The barriers were listed on a flip chart sheet and displayed on the wall. Additional barriers that were identified in subsequent sessions were added to the list. Before the CIG

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drafted the implementation strategy, the barriers were reviewed and the main barriers identified. The CIG used the identified barriers as a basis for the proposed management structure and roll-out options and the different steps in the implementation strategy.

Agreeing on the management structure and roll-out options

The CIG agreed that the roll-out of the new framework should be managed effectively and not left to the management skills and initiative of the individual PW managers. Through discussions and negotiation the CIG reached consensus on a preferred management structure. The CIG recorded the preferred management structure on a flip chart sheet and called it the "hub". The CIG then discussed the reporting lines and all the envisaged functions of the hub and listed them on the flip chart sheet. The sheet was displayed on the wall and additional functions were added as they were identified in subsequent discussions.

The CIG discussed different roll-out options based on different PW scenarios and recorded it on flip chart pages through drawings and flow charts. It was acknowledged that different PWs would need different levels of support, capacity building, resources and assistance based on, amongst others, their capacity, size, location and service user profile. The roll-out of the programmes and the framework would therefore have to be flexible to meet the needs of different PWs.

STEP 2: Drafting the implementation strategy

Since the CIG was an ad hoc group that was formed for the purpose of the study only, it was clear that it could not take responsibility for the implementation of the transformation strategy that it developed. The PW managers on the CIG were all employees of member mental health societies with permission to take part in the study for the agreed time period only. It was therefore agreed that the implementation would be done by the new management structure (hub). It was therefore important for the CIG to develop a structured and logical implementation strategy that SAFMH and later the newly appointed manager of the hub could understand and follow to ensure successful implementation. It was done through first identifying the implementation steps before organising them into implementation phases as described below.

Confirming the implementation steps

The drafting of the implementation strategy was done by the CIG through brainstorming and discussions.

For this exercise the CIG members were seated at tables arranged in a U-shape with the flip chart stand at the open end. The researcher assumed the role of catalyser by asking leading questions to stimulate the generation of ideas. Such questions included: 1) Now

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what? How do we get the framework implemented? 2) How will this be rolled out? 3) Who should take responsibility for the further development of the framework?

The ideas were recorded on the Flip Chart sheets. During the brainstorming Cycle, all ideas were accepted without evaluation of criticism. During the evaluation of the results following the brainstorming, the ideas were clarified, categorised and ranked to sift out the most practical and workable ideas that could be included in the implementation strategy.

From these ideas the different steps to be included in the implementation strategy were listed on flip chart sheets in random order until saturation had been reached and agreed upon.

Organising the steps into implementation phases to form a strategy

The CIG agreed that the implementation strategy should be presented as a chronological progression of the steps identified. Since the strategy involved different role players for the different steps and some steps built on the outcomes of others, it was decided to structure the strategy into different implementation phases. To achieve that, the CIG first numbered the steps in a first draft chronological order. This was followed by a discussion resulting in the renumbering of some of the steps (based on the outcome of the discussion and the envisaged time line of transformation) until agreement was reached on the sequence of the steps. Each step was named and more details were added to explain the purpose of the step and to highlight the importance of the step. Thereafter the steps were grouped into 9 phases to form the final implementation strategy.

3.7 Presenting the findings to the SAFMH Directors for adoption

The presentation of the findings to the SAFMH Directors was considered a very important part of the study as it provided an indication of the practical usefulness of the newly developed framework and implementation strategy in service delivery in the different mental health societies' contexts (another quality criteria identified by Meulenberg-Buskens[91]). The presentation to the SAFMH directors was also the first step towards buy-in and adoption of the framework by the SAFMH Directors. If it was not adopted for implementation and roll-out, the framework would have remained a very expensive paper exercise without any change in service delivery to adults with ID at SAFMH PWs. All CIG members were present and formed part of the presentation to demonstrate ownership and to confirm that the presentation was based on collective agreement by all the CIG members. The presentation was done through a PowerPoint Presentation. Each Director received a copy of the concept document outlining the study findings.

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The presentation was concluded with a questions session facilitated by the researcher. All the questions raised by the SAFMH Directors were listed on a Flip Chart sheet. The questions focussed around clarification of service user groups aligned to specific programme levels and how some aspects would be implemented differently between rural and urban-based populations.

The CIG handed the process over to SAFMH Directors at this stage with the assurance that they would stay committed to the process and would be available for consultation in future.

3.8 Trustworthiness

Since the collected data was mostly of a qualitative nature, the strategies used to ensure the trustworthiness of this study are described below in terms of credibility, transferability, dependability and confirmability[97].

Credibility was obtained through detailed and accurate written recording of data constructed and consensus reached on flip file sheets and in transcriptions of audio recordings, triangulation of data by comparing data collected from different sources and at different times from same sources, member checking of all documentation and progress reports by co-researchers at search conferences and through e-mail communication and the use of multiple researchers.

Transferability was obtained through thick descriptions of the SAFMH PW context and background, the legislative framework, the client base the framework is designed for and the resources available in a developing country context. Thick descriptions were circulated to all co-researchers to add to the description and to check the accuracy thereof.

Dependability was obtained through triangulation of data, digitally recorded data, the use of participant researchers and inquiry audits to ensure that idiosyncrasies of indivual CIG members would not compromise the interpretation of the data.

Confirmability was ensured by keeping a research journal and notebooks, researcher's diary, reflection diary forms kept by all co-researchers, and a research audit with thick descriptions of the process, data constructed during search conferences, findings, reflection cycle notes and planning logs. The sessions of all the search conferences were recorded and transcribed to confirm the discussions, decisions, agreements and consensus reached.

3.9 Data analysis

The data collected was qualitative data in the form of transcriptions of discussions at search conferences, meetings and other documents generated as part of the research process.

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The researcher conducted an inductive content analysis[98] of the transcriptions of the recordings of the search conference sessions and other documents including the reflection diaries, the researcher's diary and the flip chart sheets generated during search conferences as well as progress reports drafted after search conferences.

The researcher first read through all the transcriptions and other documents five times to ensure understanding of the context of the data. The researcher then used the Atlas.ti software programme[99] to analyse the transcriptions by extracting the important quotes from the text and assigning them with a code label. Once all the quotes had been labelled and the codes identified, the researcher grouped codes according to similarity and merged codes that were repetitive. The codes were then grouped into sub-categories and categories. The categories were grouped according to similarity and three themes emerged. In addition to the Atlas.ti software the researcher used MS Excel to prepare a visual representation of the codes, categories and themes.

3.10 Ethical Considerations

Ethical approval was obtained from the Health Research Ethics Committee of the Faculty of Medicine and Health Sciences, Stellenbosch University (ref. S12/05/143) to conduct the study.

Winter[95] identifies a few ethical considerations to which Action Researchers should pay attention. These include the responsibility for maintaining confidentiality, that all participants should be allowed to influence the work, that the researcher's wish whether or not to participate at any point in the study be respected, that the development of the work remain visible and open to suggestions from others, and that the principles guiding the work be accepted in advance by all.

The researcher took Winter's recommendations into account in drafting the 8 ethical considerations described below before the study. It was presented as part of the training of the CIG and adherence was monitored throughout the study by the researcher and the CIG.

The study was designed to ensure that no harm was caused to participants or co-researchers in terms of physical, emotional or financial well-being while participating in the research and data collection strategies. Co-researchers and participants did not forfeit their salaries while taking part in the study since a professional fee was paid to the employers of the CIG members for their participation in the study. Since persons with ID were recognised as a vulnerable group in research[100], the researcher ensured that the participant with ID on the CIG was adequately supported at all times while participating in the study.

All participants and co-researchers in this study were informed that participation was completely voluntary, that they had the right to refuse to participate or to withdraw from the study at any point without any harm or negative consequences to them.

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Although professional fees were paid to mental health societies to compensate them for the time lost while their employees attended research conferences, participants and co-researchers were not offered any remuneration for their participation in this study and this therefore did not influence their decision to participate.

Confidentiality was ensured in that the results of the co-operative inquiries were reported in aggregated format, reference was made to the CIG in data construction and the names and identities of individuals who had participated in the group were withheld. Participants and co-researchers were informed that they were taking part in data construction as part of a co-operative inquiry or focus group and were not named individually. Documents and transcriptions were stripped of any identifying information. Participants were given the right to review all documents to confirm that the confidentiality measures described above had been adhered to.

The best interest of participants and co-researchers was ensured through the honouring of trust, an awareness of power in relationships, by being accessible to participants, ensuring support for service users as needed, providing compensation for out-of-pocket expenses to service users on the CIG on travelling days while participating in the study, and by treating CIG members equally.

Respect was achieved through respect for the privacy and autonomy of participants and the right to their opinions. Information of CIG members and other participants was not passed on in any way.

Informed consent was obtained through the following process with CIG members and participants:

- **Disclosure**: Detailed information on the purpose of the study, procedures, data collection methods, confidentiality, reporting of results and risk/benefit to participants / CIG members was communicated through an information leaflet (Appendix D) and explained verbally as needed.
- **Voluntary participation**: Potential participants were informed that participation was completely voluntary and that they had the right to refuse or withdraw from the study at any point without any negative consequences to themselves.
- **Competence**: All participants were competent to make a decision on participation. The participating SAMHAM service user representatives underwent self-advocacy training and had at least 4 years' experience of representing persons with mental disabilities on national forums and at international congresses and were accompanied by a familiar supporter of their choice. The supporters assisted the service users with language translations and reading and writing tasks as needed as reasonable accommodation. Although all participants could speak and understand English, not all participants were English first language and translations were arranged as needed by another CIG member to ensure understanding.

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The CIG members were asked to sign a written consent form (refer to Appendix E) before taking part in the study. These forms were filed and kept by the researcher.

Justice was achieved through no discrimination for inclusion, by providing translators and supporters as needed and by not creating unfair expectations on the part of CIG members or participants of remuneration or quick-fix solutions to problems.

Through transparency and reflexivity, the researcher and CIG members avoided deceptive practices by ensuring that participants knew and understood the processes, data collection strategies and were kept informed throughout. Participants were informed that they had the right to review all documents pertaining to their participation for accuracy and confidentiality.

3.11 Summary

Chapter 3 described the methodology of Action Research with Co-operative Inquiries as used in this study. It gave an overview of the context of the study, the participants and the data collection strategies.

It further described the four AR Cycles of the study, including the planning and preparation of the study, the development of the framework outline, the development of the programme levels and pathway the development of the implementation strategy.

It went further to describe how trustworthiness was ensured and described how data analysis was performed. The chapter ended with a description of the ethical considerations relating to the study and its participants.

Chapter 4 will describe the findings of this study followed by Chapter 5 that contains the discussion, conclusion and recommendations.

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Chapter 4 FINDINGS

4.1 Introduction

The previous chapter described the methodology of Action Research with Co-operative Inquiriy as used in this study. It gave an overview of the context of the study, the participants and the data collection strategies. It described the four AR Cycles of the study, described how trustworthiness was ensured and data analysis was performed. The chapter ended with a description of the ethical considerations relating to the study and its participants.

In this chapter the findings will be outlined. The findings include new knowledge and a transformation strategy (consisting of a service delivery framework and an implementation strategy) for future service provision at SAFMH PWs.

4.2 Overview of the findings

The new knowledge was constructed from the data through inductive content analysis. Two themes with categories and sub-categories were identified from the data. These findings will be illustrated with quotes from input given by individual CIG members during the discussions and drafting of the new SAFMH framework and implementation strategy. The quotes used in this chapter represent the group consensus reached during discussions, unless specified that a particular quote is the opinion of an individual.

In addition to the quotes, the findings will be illustrated with diagrams and tables outlining the proposed new framework and implementation strategy drafted. The products of the study (the framework and implementation strategy) were recorded in a concept document and PowerPoint presentation that were presented to the SAFMH Directors at the end of the study. Extracts from the concept document and presentation were included in this chapter as evidence of the developed framework and implementation strategy.

In this study the researcher regards the transformation strategy as a collective of the framework and an implementation strategy that was developed by the CIG as part of this study. The term framework is used since it was not yet implemented. It should be noted that the CIG referred in their discussions to the new framework as the “best practice model” or “model”. The researcher refers to the suggested strategy for implementation of the framework as the “implementation strategy” even though the CIG referred to it as the “transformation strategy”.

The CIG considered the CMH Model that was given to them as a template for the development of the SAFMH framework of best practice, and decided on the components that could be included and those that would need adaptation or redrafting. Please refer to Appendix H for a summary of the outcomes.

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The two themes that emerged from 8 categories and 19 sub-categories were:

Theme 1: Comprehensive Service Provision

Theme 2: Coordinated transformation of services

Figure 4.1 illustrates the two themes with their categories and sub-categories.

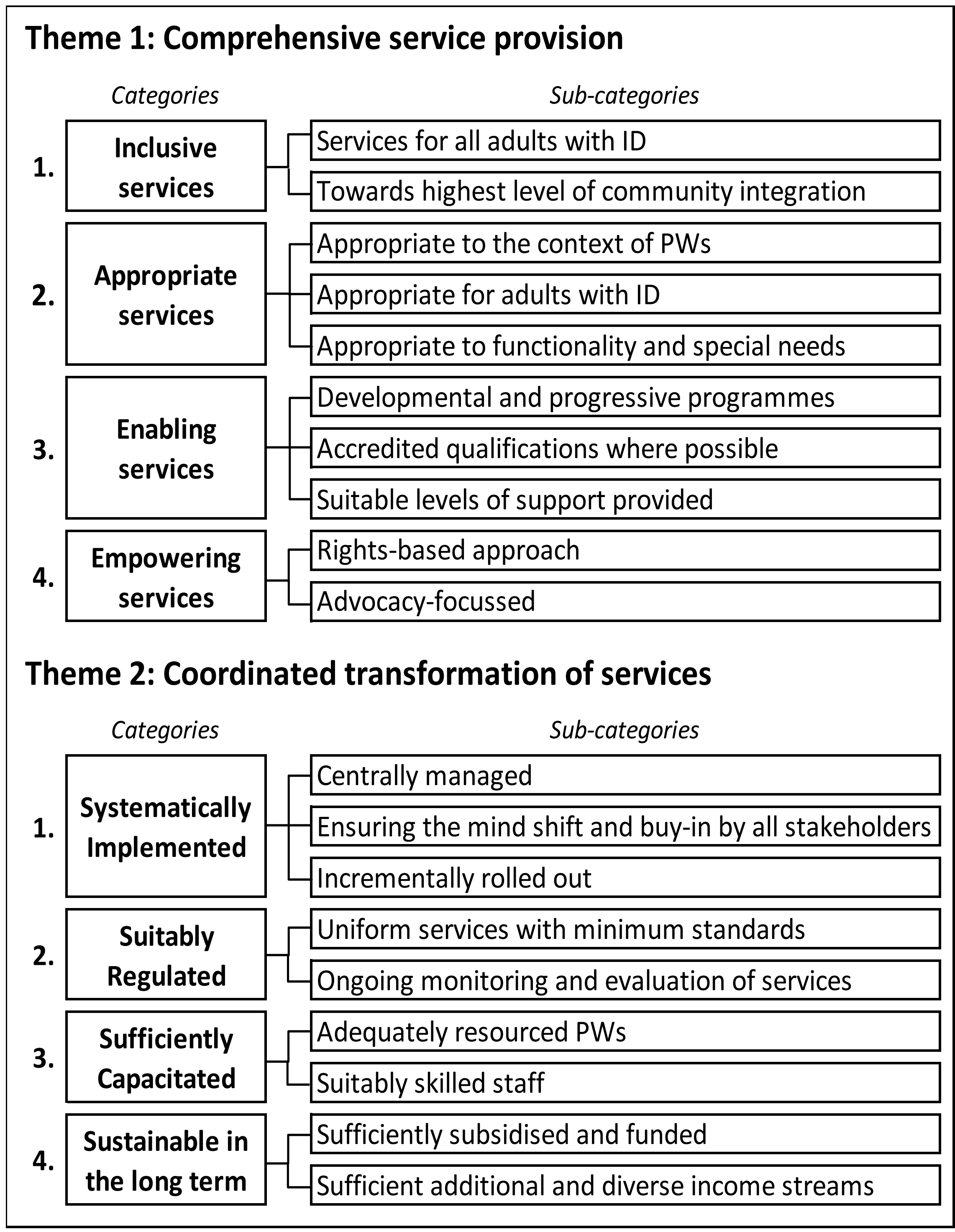

Figure 4.1 The two themes with its categories and sub-categories

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4.3 Description of themes, categories and sub-categories

4.3.1 Theme 1: Comprehensive Service Provision

This theme emerged from the sub-categories and categories of codes that relate to the nature of the service to be provided to service users with ID at SAFMH PWs (refer to Figure 4.1). This theme consists of 4 sub-categories:

- Category 1: Inclusive services
- Category 2: Appropriate services
- Category 3: Enabling services
- Category 4: Empowering services

Category 1: Inclusive services

This category was formed from two sub-categories, namely:

Sub-category 1: Services for all adults with ID

Sub-category 2: Towards highest level of community integration

Sub-category 1: Services for all adults with ID

From the presentation of current programmes offered at SAFMH PWs, it was clear that most PWs provided services to persons with mild and moderate ID only and that the admission criteria excluded persons with severe and profound ID from service provision. It was further confirmed that there are no designated care or training programmes available in South Africa for adults with severe and profound ID, resulting in isolation and a high burden of care on the caregiver and family. It was reported that in most provinces these adults remain at the Special Education and Care Centres for children with severe and profound ID. It was agreed that the SAFMH framework should provide for services for adults with ID, including persons with severe and profound ID, to allow them to access services as adults. This is illustrated by the quotes below:

"A lot of the workshops have not actually thought about this [programmes for persons with severe and profound ID]; they just took it for granted that the Special Care Centres will keep them on or that they will go home to nothing" (CR6)

"They [persons with severe and profound ID] have the right to be amongst adults; why should they be amongst children all the time?" (CR1)

"It is very hard on the caregiver who needs to care for this person [with severe and profound ID] 24 hours per day … and it is very hard on the person [with severe or

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profound ID] and the caregiver because they cannot go out of their houses; they are like prisoners in their own homes. They get very isolated." (CR6)

"We want to include this [programme for persons with severe and profound ID] in our [SAFMH] model [framework] because there is a need and there is nothing for this specific group, no programme provision" (CR1)

"These people [with severe and profound ID] need higher levels of care. At the moment the workshops only make provision for people who are toilet trained. There are no nursing assistants in place to assist people with toileting or nappy changes or feeding and that's an under-serviced part of intellectual disability. So we would like to give them a day programme and offer them the same opportunities that other people got with the necessary care in place." (CR2)

As a result of the decisions demonstrated above, a programme that would provide higher levels of care (assistance with self-care and activity participation) was included in the framework as will be discussed further down in this chapter.

Sub-category 2: Towards highest level of community integration

After the presentation on the rights of persons with ID it became clear that persons with ID have the right to integration and inclusion into their families and communities. It was agreed that programmes need to include training towards and support for the maximal level of community integration possible, including information on safety and preventing abuse. The following quotes from CIG members confirmed the group consensus:

"People [with ID] were previously institutionalised and must now re-integrate into the community and this is now a new need where they [persons with ID] need to learn to live with their families and in the community." (CR6)

"Support and integration [of service users with ID] does not only apply to the programmes within the workshops … It includes participation in community activities." (CR3)

" Our trainees [service users with ID] live in the community with family, they go to church, shop at the shopping centres, do sports; they are part of the community. We have to train and support them to do that." (CR7)

"It is a huge jump from Protective Workshop [to integration into the community] because it's from a protected situation to [go] out there in the world … with support, but it's tough. We need to prepare them [persons with ID] for it." (CR1)

"They [persons with ID] live in the community where they are quite vulnerable, most of them. [We see] abuse, signs of real physical and sexual abuse. They need to learn

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and know how to look after themselves. We have to teach them about their bodies and that they can say no." (CR5)

Based on the views of participants demonstrated above, it was decided to include community participation skills in all the programme levels. This could include training on the use of community resources (such as postal services, police services, the library, shops and public transport) and outings to allow service users to practise their newly acquired skills. Sexuality education and the right to say no were also regarded as important to include it in all programme levels.

Category 2: Appropriate services

It was agreed that persons with ID need services at PWs that are appropriate in terms of the context of PWs and the needs of the adults with ID. The PWs in the past tried to simulate the mainstream world for persons with ID since they were mostly excluded from mainstream living and regarded and treated as children. It therefore offered a paralleled society to persons with ID simulating work, play and leisure in a segregated context. Since persons with ID now have the right to work in the open labour market and integrate into society, services at PWs should no longer pretend to be employment. PWs now have to ensure that their services are appropriate to the context they operate in and the status and needs of adults with ID.

This category was formed from three sub-categories, namely that services should be:

Sub-category 1: Appropriate to the context of PWs

Sub-category 2: Appropriate for adults with ID

Sub-category 3: Appropriate to functionality and special needs

Sub-category 1: Appropriate to the context of PWs

The PWs are service providers to persons with disabilities. The services provided to persons with ID by most SAFMH PWs were reported to include respite care, a safe haven, participation in arts and craft activities or involvement in repetitive assembly tasks in the form of subcontracted work from factories and corporates. The persons involved in these production activities usually receive a small incentive in the form of a weekly stipend or allowance. The income derived from the contract work is mainly used to sustain the PWs and complement the subsidy income. Due to this production component PWs are often referred to as protective employment for service users with disabilities. This leads to the incorrect assumption that service users are employed by PWs as evident in the quote below:

"The social workers refer the people to the workshop and tell them the workshop will give them a job." (CR6)

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This misconception is further strengthened by staff referring to PW service users as "workers", the stipend they receive as "wages" and the staff as "supervisors" – along with other references to the PW being a work environment; these are illustrated in the quote below from feedback given during the presentation of current practice at SAFMH PWs:

> *"The workers [service users with ID] work on contract work and earn a small weekly wage based on attendance and production. The supervisors have to ensure that the deadlines are met and the quality is aligned with the requirements." (CR3)*

The perception that service users are employed by PWs creates unrealistic expectations on the part of service users and their parents/caregivers that they will be earning a salary. The allowance or stipend paid by most PWs to service users involved in production is a small monetary incentive and not a salary. This may lead to disappointment and a perception that service users are being exploited, as illustrated by the quotes below:

> *"If they think they are workers, they want a salary and workshops cannot pay them market-related salaries. The income we make from the contract work they do is not even enough to break even." (CR2)*

> *"Then the parents complain and say that the people work every day the whole day at the workshop, but at the end of the week they only get pocket money. They say we are taking advantage of them." (CR7)*

In contrast to the above, not all service users are attending the PWs to be involved in production. For some the PWs provide a safe haven, as illustrated in the following quote:

> *"Most of the lower functioning people [with moderate and severe ID] attending our workshops, their main motivation for coming is to have a safe place to spend their daily hours while their family is away at work. It's not really to come and work." (CR1)*

It was therefore concluded that the perception that service users are employees of PWs is incorrect, since PWs are non-profit organisations providing a welfare service to the service users. In reality, this service could include care, training, support, job coaching and mentoring. In addition it could provide the service users with a safe space where they could engage with others.

During the CIG discussions following the presentation and unpacking of the CMH model, consensus was reached that PWs are, in fact, training facilities using a simulated work environment for work habilitation. The service users are therefore not employees, but adult learners in a training programme, as illustrated by the following quotes:

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"We [PWs] are using contract work for two purposes: firstly, to simulate a realistic work environment where work training can be done and, secondly, to generate income to keep the doors open [to sustain the PW financially] and to pay the service users a stipend to keep them motivated and to teach them how to work with money." (CR1)

"We [PWs] are training them [service users with ID] how to work; we are training them how to follow instructions; we are training them how to work with money and how to behave appropriately in a work place. If they only attended the workshop to work on contract work, it would have been exploitation, but they don't. They learn new skills and behaviour that they would need to be employed when they leave the workshop …" (CR2)

"… just like universities don't call their students workers; they call them students, because they are still learning how to do the job; they are not employed." (CR1)

This shift in status, from viewing service users as workers to recognising them as learners, suggests changes to the nature of the service offered by PWs, from providing employment to providing training and development to adults with ID. The programmes offered at PWs must therefore be appropriate to the context of PWs as training providers and not as employers of persons with ID.

Sub-category 2: Appropriate for adults with ID

This sub-category refers to the agreement by the CIG that all service users at SAFMH PWs are adults and that the services provided should be appropriate for adults with ID.

Despite the fact that all service users registered at PWs are 18 years and older, the service users with ID are often referred to and treated as if they were children. This includes calling them patronising names like "baby" or "dearie" and not giving them the respect and status of adults as in the case of the workshop staff. It resulted in an uneven relationship where service users are seen as dependents, unable to make decisions for themselves and in need of care and protection. It further led to the use of training materials developed for toddlers and small children being used in PW programmes to teach basic concepts to adults with ID.

The following quotes serve as illustration:

"They [persons with ID in PWs] are grown-up people; they are 18 years and older. Adulthood for other people [persons without ID] is based on their reaching a certain age, not the fact that they can take full responsibility for their lives or that they make responsible decisions." (CR7)

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"We [the PW management and staff] should treat the people in our workshops [PWs] as adults. They [the service users with ID] have the right to grow up; they are not children for life." (CR2)

"We [the CIG developing the framework] need to be very sensitive to the fact that we are working with adults. The whole programme needs to be oriented to adults." (CR3)

It was concluded that changing the way in which service users are perceived will have an impact on the expectations and outcomes of the programmes included in the new framework for PWs. The programmes, including content and teaching methods, should be oriented to adults. Programmes should therefore include adult topics (for example sexuality education) and training materials should contain pictures of adults that service users can identify with and not those of toddlers and children used in most existing training materials for basic concepts.

Sub-category 3: Appropriate to functionality and special needs

The diagnosis of ID covers a wide spectrum of functional abilities through the different degrees of mild, moderate, severe and profound ID. The functional abilities of the service users determine their special needs for support and training. Despite the different needs of the service users, it was reported (at the workshop held in February 2011) that most SAFMH PWs offer a single programme. Despite their very different needs and level of functioning, the highest functioning and lowest functioning service users were expected to participate and benefit from the same intervention. It was agreed that the training and special needs of persons with ID were aligned to their functional abilities and that these could not be addressed in a single programme with only one set of outcomes.

To ensure that the framework will be appropriate to the functionality of the current service users at SAFMH PWs, the CIG identified six service user groups according to the current functional abilities and special needs (refer to Appendix G).

It was agreed that the functionality of the identified service users' groups should guide the development of programmes at six different levels to ensure inclusion of all persons with ID currently registered at SAFMH PWs. The framework developed therefore includes 6 different programmes with different outcomes based on the needs and abilities of the 6 service user groups described above. It was decided to refer to these different programmes as "Levels". This is illustrated in the quote below:

"… at the moment most [protective] workshops have a single programme structure, where everybody comes, they do the same thing, they get the same training and they leave and it's not suitable for the different levels of functioning [of the service users with ID]. We envisage transforming to 6 different levels of programmes." (CR3)

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It was further agreed that persons with ID have special educational needs and require special training methods and materials for optimal learning to take place. In the absence of suitable training materials, the CIG realised that SAFMH would have to take responsibility for the development of the courses and training materials to be used in the SAFMH framework levels. This is illustrated by the following quotes:

"They [persons with ID] learn through special training methods." (CR7)

"The problem is that it is not like going to a training provider and asking them to develop the training materials. We need the input from specialists on the training of [adult] learners with intellectual disability …" (CR1)

It was confirmed that the scope of the study would not allow for the development of the training materials and that SAFMH would have to secure funding and commission the development of the training materials as a next phase, as can be seen from the quotes below:

"To expect us to develop a whole curriculum, plus Lesson Plans, plus Assessments, plus everything that someone can just take away and go and implement, is unrealistic for the time frame and the amount of time that we spend as a group face-to-face." (CR2)

"It [the development of the training materials] is outside the scope of our work. It's a massive amount of work. Funding will have to be secured. Someone needs to be commissioned." (CR2)

Category 3: Enabling services

This category was formed from three sub-categories, namely:

Sub-category 1: Developmental and progressive programmes

Sub-category 2: Accredited qualifications where possible

Sub-category 3: Suitable levels of support provided

Sub-category 1: Developmental and progressive programmes

Based on the functionality and training needs of the six service user groups (refer to Appendix G), it was decided to draft the framework as six programme levels aligned to the six service user groups. The six programme levels were given generic names based on the main outcome of the level as follows:

Level 1: **Higher Care** for service user group 1

Level 2: **Life Skills** for service user group 2

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Level 3: **Work Skills** for service user group 3

Level 4: **Bridge to the open labour market** for service user group 4

Level 5: **Supported Employment** for service user group 5

Level 6: **Supported Self-employment** for service user group 6

The CIG reached consensus that persons with ID can learn and develop and are therefore able to progress from one programme level to the next when they have mastered the skills of their current level and are ready for the challenges posed by the next level. The programme levels should therefore be aligned to form a progressive training and career pathway. The six programme levels were therefore arranged in a pathway to form the framework outline for the transformation of comprehensive service delivery to individuals with ID in PW (as can be seen in Figure 4.2 below):

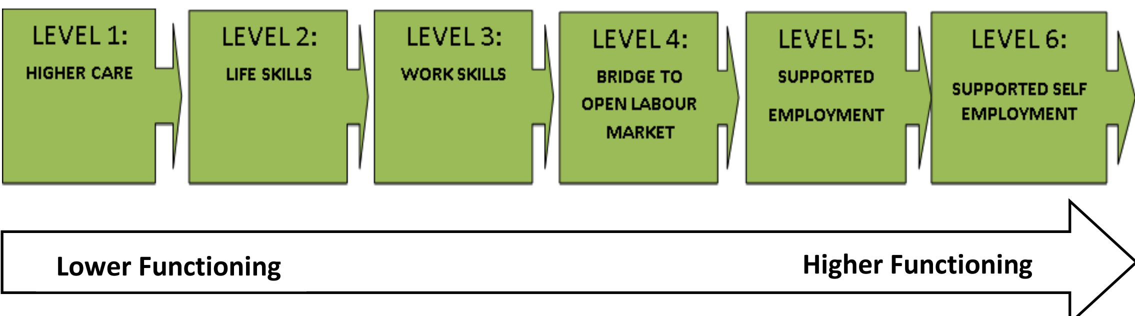

Figure 4.2 The SAFMH Framework of Best Practice with progressive programmes[96]

It was agreed to leave an arrow after Level 6 to indicate that more levels should be developed and added in future, based on the future needs of the service users with ID and new opportunities that might arise.

It was further agreed that this does not mean that all persons with ID will start at the lowest level and progress to the highest level. It means that the service users will learn and develop at their own pace to the maximum level possible according to their own abilities. The following quotes serve as illustration:

> *"We will have to go for a developmental approach … our programmes [levels] must be progressive and form a training and career path." (CR1)*

> *"Everybody [service users with ID] coming into the workshop does not start at the same level … they start at the level that is aligned with their level of functioning and their training needs at the time." (CR7)*

> *"People [with ID] will move within their capabilities and at their own speed … towards their maximum level of functioning." (CR2)*

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"When an opportunity like this arises [to progress to the next programme level], it's almost as if you can see the ones who are ready. They almost pick themselves, because they start to stand out from the group. They start to show that potential. If someone doesn't really stand out, then maybe they're not ready for this step [progressing to a programme at a higher level]. They start to talk about going forward; they start to dream about being on that side in that programme. They start to ask when they can move up." (CR1)

It was agreed that each level would need appropriate and objective assessment tools to determine at which level the service user should start, to measure progress within the level and to determine if the service user is ready to move to the next level.

"We need to include assessments – assessments to determine into which level to place the person, how they grow in the level and when they are ready to move on." (CR2)

"So that's why it's very important to have an objective assessment tool so you don't go on the persons' appearance, their social skills or their ability to fend for themselves." (CR1)

"It [the outcome of the assessment] is not to say you [the service users] are going to stay here [the level initially placed in] for life. You say: at this point, based on this assessment, you are channelled this way [into this level]. The next assessment will show if the person has developed or if the person is ready to move to the next level." (CR3)

Sub-category 2: Accredited qualifications where possible

It was confirmed that service users with ID have difficulty competing for employment since they do not have the necessary qualifications and skills required. Since they apply for entry-level jobs (like those of cleaner, gardener or packer) they compete with a large part of the unemployed population who have not had formal education. It was agreed that an accredited qualification – accredited by the South African Qualifications Authority (SAQA) – may assist the service users with ID to secure employment in the open labour market. The difficulty for service users with ID to obtain an accredited qualification is that most accredited training providers are not equipped to train and assess persons with ID. This led to the decision that PWs should offer accredited training as part of the SAFMH framework to enable service users to obtain an accredited qualification. PWs will then have to be accredited by the Sector Education and Training Authorities (SETAs) as the training provider for the selected qualifications. This is illustrated in the quotes below:

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"There [in Levels 3 and 4] should be Career Skills Training, preferably accredited and counting towards a qualification." (CR1)

"We will have to put a course together that people [with ID] can enter into and achieve a qualification [accredited by SAQA]." (CR3)

"So we're looking at 120 credits – spread it over 3 years in Level 3. It should cover all the necessary unit standards so the service users are able to achieve a qualification, as for example a commercial cleaner or a gardener or a packer. That will help them when they apply for a job in one of those areas." (CR1)

"In our model we [PWs] are the training providers with the necessary accreditation to offer the courses, because we are the specialists in training persons with Intellectual Disability." (CR3)

It was agreed that not all programme levels would lead to an accredited qualification, but that the training in levels 3 – 6 should preferably be accredited for learners to achieve credits towards a SAQA accredited qualification.

Sub-category 3: Suitable levels of support provided

In the discussions of the CIG it was confirmed that support forms a key aspect in the development of persons with ID. It was agreed that the support required would be determined by the level of functioning of the person with ID and their aspirations and dreams determining the outcomes to be achieved. The support needed and provided in Level 1 would therefore be very different to the support needed and provided in Level 6. This is illustrated by the quote below:

"Support to a person with ID could be anything from assistance to do the basic self-care activities or to take part in an art activity for the lower functioning persons with ID. But it can also be the job coaching the higher functioning person [with ID] needs to cope in an interview to secure a job or to settle in at a new work place. It is any intervention needed to enable a person with ID to achieve an outcome." (CR1)

Job Coaching was confirmed as a form of reasonable accommodation in the employment of persons with ID and therefore essential in the programmes with a work rehabilitation and employment focus (Levels 3 – 6). The discussion confirmed that just enough support should be provided to enable the person. Overprotection should be avoided and support adjusted to the support needs as the person progresses. The following quotes from the PW managers on the CIG support the above:

"You can see the amazing abilities that come out, if the right level of support is provided." (CR2)

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"Job coaching and support in the workplace is written into the Technical Assistance Guide to Employing Persons with Disabilities, attached to the Employment Equity Act as a form of Reasonable Accommodation for persons with Intellectual Disabilities." (CR1)

"… that [overprotection] is not helping them [persons with ID]. … just enough support [should be provided] to enable them [persons with ID]." (CR6)

"Initially they need a lot of support, but later the job coach needs to fade otherwise the person becomes too dependent. The tasks must still provide a challenge to the person; the job coach should not make it too easy for them, [since] then they lose interest." (CR1)

The following quote from a service user on the CIG who is employed and has access to support by a job coach, provides further motivation for suitable support for persons with ID:

"My life without having a job coach would actually be very difficult. Knowing that there is someone that I can confide in, who is there when I ever need assistance. She is there for my best interest … If I can't, or if I do not have the courage to talk to them [the employer and supervisor at work] then she [the job coach] will assist me to talk to them so they can understand me better." (CR7)

Category 4: Empowering services

It was agreed that the service offered must empower the service users with ID to access their rights and speak for themselves.

This category was formed from two sub-categories namely:

Sub-category 1: Rights-based approach

Sub-category 2: Advocacy-focussed

Sub-category 1: Rights-based approach

It was agreed that the new framework must be based on the human rights of persons with intellectual disability as outlined in the UNCRPD. The CIG therefore continuously evaluated and reflected on the developing framework and programme levels to ensure that the framework stayed aligned to a rights-based approach. The service user with ID was also briefed by her supporter that she was representing persons with ID on the CIG and should therefore ensure that their rights are considered throughout. The quotes below clearly reflect awareness of a rights-based approach:

"They [persons with ID] have the same rights as all South African citizens." (CR7)

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"[To ensure that the new framework and programmes are aligned to the rights of persons with ID] she [the service user with ID] should ask: Is that what people with intellectual disability want? Is that in line with the rights of people with intellectual disability?" (CR1)

"[It is] very important for the development of the best practice model [framework] that they [the Directors, PW managers and staff] buy in to the equal status and equal rights of their service users." (CR2)

It was agreed that the new service framework should take into account the equal status and rights of persons with ID and include training to empower them to access their rights.

Sub-category 2: Advocacy-focussed

Following the presentation on the United Nations Declaration on the Rights of Persons with Disability and the CMH, it was agreed that the SAFMH programmes and framework should have an advocacy focus. During the CIG data construction discussions it became clear that self-advocacy is based on knowing what one wants and prefers. Due to the perception that persons with ID are children for life (refer to *Appropriate for adults with ID* on page 66), most persons with ID do not get opportunities to make choices or express preference. It was therefore decided that the programmes should provide service users with opportunities to make choices and communicate preferences as can be seen from the quote below:

"We have to provide them with and assist them [service users with ID] to make choices. They are so used to their parents making all the decisions for them and that is not right. For the lower-functioning ones it may mean giving them two options that they can cope with. For example, we could ask them what they would like to have on their sandwiches: peanut butter or Marmite. For the higher-functioning ones we need to have different training options so they could choose if they want to learn how to become a cleaner or a gardener. [We should] not just tell them what to do." (CR1)

It was further decided that advocacy training and opportunities to speak for themselves and represent persons with ID on different forums should be included, as illustrated in the quotes below:

"Our programmes have to include training on advocacy skills so they can speak for themselves. Like at Cape Mental Health, they should be able to have a committee and have meetings to inform management on what they want at the workshop." (CR2)

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"We should train and support them [service users with ID] to represent persons with ID on the Boards of the mental health societies, the SAFMH Board and other forums like government summits and workshops." (CR1)

Based on the above, advocacy training and support for self-advocates were included in the programmes in the framework based on the service user participation model at Cape Mental Health. This includes the introduction of a service user committee at each PW consisting of persons with ID who were elected by their peers. Each committee is supported by an advocacy support person. In the CMH Model the chairpersons of the different PW service user committees form the service user council. Each person is supported by a particular committee supporter when attending council meetings. The chairperson of the service user council (elected by the council members) represents persons with ID on the CMH Board. This Board Member has a designated advocacy supporter to assist with preparations for Board Meetings (including understanding the agenda and minutes of the previous meeting and compiling a report) and reporting and participating at the meeting. At CMH these supporters are PW staff members who received training on the role and duties of the supporter.

4.3.2 Theme 2: Coordinated transformation of services

After the initial discussions on the CMH model and the envisaged new SAFMH framework (with different programmes for different service user groups) during Phase 2 of the study, it became very clear that a structured implementation strategy would be needed to ensure successful implementation. This is supported by a reflection diary entry made by the researcher:

"It took some time for some of the CIG members to get their heads around the need for different programmes for different groups of service users allowing for progression in a pathway. It was as if they just could not imagine it within their current frame of reference." (CR1)

This was confirmed in a follow-up group reflection session by the following comment by a CIG member:

"To me it [different programmes in a progressive pathway] was like abstract and I wondered if we could do it. It was so interesting for me to see how I could not visualise it; I could not see it taking shape." (CR2)

"The model that we are developing is really a complete change from how we are operating currently and we will have to help the managers, staff and service users step by step to make it happen. If it was difficult for us to grasp, just think how much assistance they would need." (CR3)

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The above confirmed the need for an implementation strategy to prepare and assist the PWs to implement the new SAFMH framework successfully. The final implementation strategy that was agreed on consisted of nine phases, as illustrated in the slide in Figure 4.3 below (extracted from the PowerPoint Presentation presented to the SAFMH Directors in March 2013). It will be described in more detail as part of this theme.

TRANSFORMATION STRATEGY

- **Phase 1**: Buy in from SAFMH Directors
- **Phase 2**: Get buy-in from Government Departments
- **Phase 3**: Secure initial funding for establishing hub and programme development
- **Phase 4**: Establish "Hub"
- **Phase 5**: Secure funding for piloting
- **Phase 6**: Sector buy-in
- **Phase 7**: Implement pilot studies
- **Phase 8**: Secure funding for national roll-out
- **Phase 9**: Roll-out

Figure 4.3 The slide on the Implementation Strategy (referred to as the Transformation strategy by the CIG)[96]

The second theme, Coordinated transformation of services, therefore emerged from the sub-categories and categories of codes that relate to the transformation from current status to the envisaged new SAFMH framework at SAFMH PWs. Please refer to Figure **4.1** for the categories and sub-categories that informed this theme.

Theme 2 consists of four sub-categories namely that services should be:

- Category 1: Systematically Implemented
- Category 2: Suitably regulated
- Category 3: Sufficiently capacitated
- Category 4: Sustainable in the long term

These categories will be discussed in detail below.

Category 1: Systematically Implemented

This category was formed from three sub-categories, namely:

Sub-category 1: Centrally managed

Sub-category 2: Ensuring the mind shift and buy-in by all stakeholders

Sub-category 3: Incrementally rolled out

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Sub-category 1: Centrally managed

It was agreed that the CIG would not be in a position to take responsibility for the further development, roll-out and monitoring of the framework. It was therefore agreed that the transformation process should be coordinated and managed by a central hub located at the SAFMH National Office with full-time staff employed.

The slides below (Figure 4.4) on the Hub and the Hub Functions were extracted from the PowerPoint Presentation drafted by the CIG for the presentation to the SAFMH Directors in March 2013:

ESTABLISH HUB

- Located within SAFMH
- Reporting to SAFMH
- Operational responsibility
- Implementation of pilots and roll-out
- Securing funding
- M&E / Q&A
- Ongoing evaluation of the model and adaptations as needed

HUB FUNCTIONS

- Project Management
- Programme Development
- Donor Development (for hub and roll out)
- Organisational assessment
- Organisational capacity building and training
- Quality Assurance
- Monitoring and evaluation
- Marketing and Branding
- Administration and reporting
- Financial Management
- Networking

Figure 4.4 The slides on the establishment and functions of the Central SAFMH Hub[96]

It was agreed that SAFMH would secure initial funding for the establishment of the hub. Once established, the SAFMH Central Hub would take full operational responsibility for the further development of the framework and programmes (including training materials and assessments), securing funding for piloting, facilitating buy-in from the sector (including PW managers and staff, service users and parents), implementing pilot studies, securing funding for national roll-out, and managing the roll-out including continued quality assurance.

Sub-category 2: Ensuring the mind shift and buy-in by all stakeholders

From as early as AR Cycle 2, during the discussions on the outline of the framework, it was identified that the SAFMH Directors, PW managers and PW staff would need a mind shift before successful transformation could take place. The areas in which mind shifts would be needed were identified to be the following:

- The way service users are perceived and treated: The fact that they are adults and not children for life (refer to *Appropriate for adults with ID* on page 66)
- The fact that PWs are not employers of the service users or viable business units, but development and training centres (refer to *Appropriate to the context of PWs* on page 64)

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- That the PWs are not there to protect the service users against the world, but to equip and support them towards maximum level of integration (refer to *Towards highest level of community integration* on page 63).

The need for a mind shift of the different stakeholders is demonstrated by the quotes below:

> *"We realise that it's not going to be a quick fix. We're not doing this [develop the framework] and then in January we tell the workshops this is what they need to do and suddenly everybody is going to transform and have everybody up and running by June next year. It's not going to be like that." (CR3)*

> *"In order for them [the SAFMH PW sector including directors, managers and staff] to accept our model there will have to be some mind shift changes." (CR2)*

> *"We must first [before we can implement the model] succeed in getting them to make the mind shift." (CR4)*

> *"... changing the thinking patterns of the people, from 'We need to make more money' and 'We need to get more machines', to the new focus of developing and training persons with intellectual disability." (CR3)*

> *"There needs to be a complete mind shift in the people who are placing the unbearable expectation upon us [to generate income from contract work], that we are actually not income generating, we're training providers. The tension is always there, because of the pressure for income. The reason why we exist is not because we are the best manufacturer of whatever x, y and z [products manufactured by the PWs]." (CR3)*

If was decided that this mind shift would have to be facilitated and managed. The following quotes illustrate this decision:

> *"The ability of the workshop staff to make the [mind] shift may be a challenge. There will have to be up-front training, because they need to understand; they need to make a mind shift." (CR2)*

> *"As much as presenting the model [framework] and giving the whole background is important, I think what we really need as an outcome of that presentation [to the SAFMH Directors], is for them to get onto this path of starting to see things differently. So even if we don't manage to give all the information in that time, as long as we can succeed in getting them to start making the mind shift." (CR3)*

> *"We must include a session on the mind shift in the programme for the presentation to the directors, but also when we want buy-in from DSD and the PW managers, and the staff and service users, even the parents." (CR4)*

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Based on the above, a session to facilitate an understanding of the mind shift needed was included in the presentation to the SAFMH Directors and is planned as part of obtaining buy-in from the sector including staff, parents and service users.

Sub-category 2: Incrementally rolled out

The CIG realised that the roll-out would be a long process that has to be coordinated and managed by the SAFMH Central Hub and done in an incremental manner to ensure successful implementation. The importance of first piloting the newly drafted framework of best practice programmes was confirmed in the following quotes:

> *"You are not going to take something that you just developed and thought out and roll it out. First you have to do it with a few, maybe a rural and an urban [protective workshop] and see how it works. Then you are going to adapt and fine tune it first before rolling it out." (CR3)*

> *"I definitely feel that there should be some Pilot Studies done, as part of the roll-out." (CR2)*

It was therefore agreed that, even though the full framework consists of 6 programme levels, the programme levels could be rolled out individually, aligned with the organisational capacity and the service user needs at each PW. The PWs can therefore decide which level(s) they would like to implement, as can be seen in the following quotes:

> *"Not all the workshops would be able to offer all of the programmes as from the word go. They may start with one level only and add more levels as they are able to cope with more and as their service users are ready to engage at the next level." (CR3)*

> *"Not every organisation is going to have all 6 levels. We cannot tell organisations what services they have to offer in their region. They may say: 'In our context and our reality we are only going to buy into levels 3 and 4 only'. Or they may say: 'We are not ready for that level or that level would not suit our client base'." (CR1)*

It was further agreed that the Central Hub would have to perform an organisational assessment to establish the ability of each PW to implement the levels it chooses. Based on this assessment the Hub could grant permission to the PW to offer the level or deny permission pending further development and resourcing. This is illustrated in the quote below:

> *"The organisation [PW] decides what levels it wants to offer, but the Hub assesses and considers and grants the appropriate license [permission to implement specific levels] to the organisation. If the assessment showed that the organisation is not ready, then the Hub would not give them a license, but rather development and assistance to get the things they do not have." (CR3)*

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For the first time in this study, there was strong disagreement between one member and the rest of the members of the CIG when it came to the preferred assessment and streaming of the service users and roll-out method to transform at a PW level from offering a single programme to offering multi-level programmes.

The majority of the CIG members agreed that it would be best for PWs currently offering a single programme (most of the SAFMH PWs) to initially transform by streaming their service users into two main groups based on the outcome of a functional assessment (the opinion of the disagreeing member will be discussed further down). The two groups would be: one group made up of those that primarily need care and stimulation (aligned to service user group 2) and the second group comprising those who are able to perform work activities (aligned to service user group 3). It was further agreed that those workshops should start implementation by offering only Level 2 (Life Skills) and Level 3 (Work Skills) of the SAFMH Framework.

These PWs could then gradually and incrementally increase the number of levels as the service users develop and become ready to enter into the next level.

Figure 4.5 is a graphical representation (copied from the flip chart drafted during the discussion) of how this incremental roll-out could potentially be done.

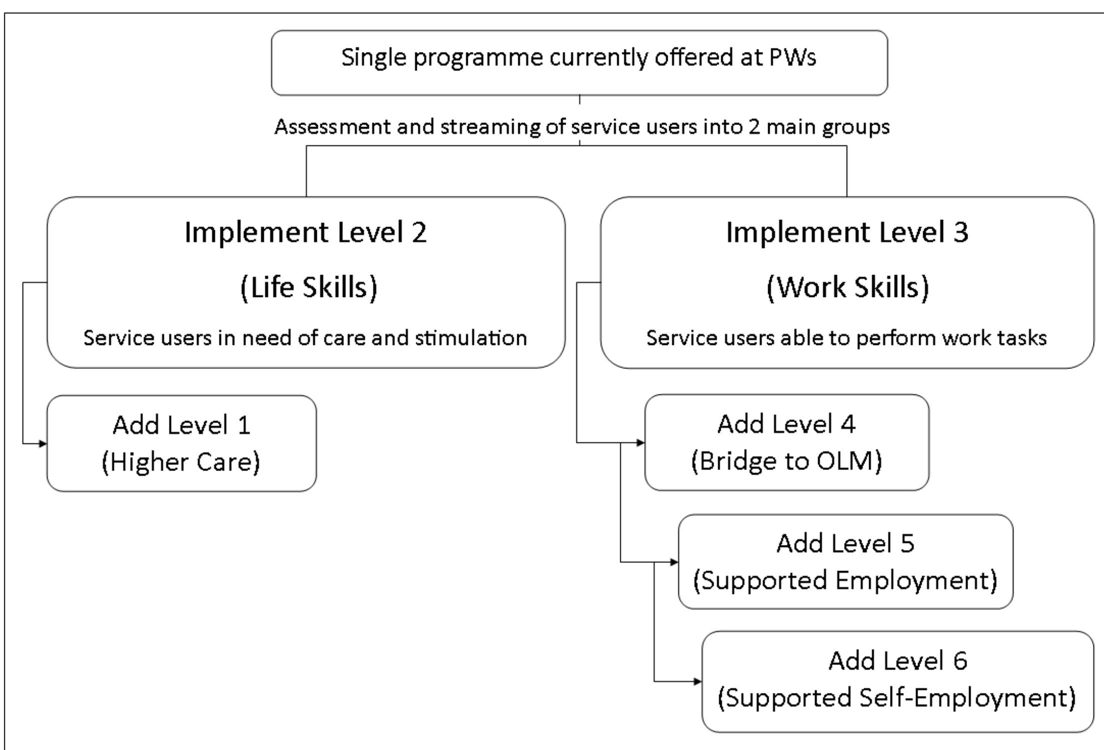

Figure 4.5 Proposed incremental roll-out from a current single programme to implementation of multiple programme levels

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One CIG member strongly disagreed, as can be seen in the following quote:

> *"The whole idea of us doing this new model, is that it is going to shock people into a completely new method of working and if we're going to be nursing them through an intermediate step [of only offering some of the programme levels initially], then I cannot understand. They are going to carry baggage from where they were, into the best practice model." (CR3)*

Consensus was reached once the member understood that the PW that the member manages has already streamed service users into some of the service user groups and would therefore more readily engage in more of the levels from the start of transformation, but that most PWs would need to start at the very beginning by assessing the level of functioning of their service users for the first time as illustrated by the following quote:

> *"You [your PW] have already diversified. You are not there [at the very first step of transformation]; you're not starting there. You may be starting there [at the point after the initial streaming of service users into groups of those in need of care and those with a focus on work and employment]. So you are not starting there [at the very first streaming exercise], but most of them are starting there." (CR1)*

It was then agreed that those PWs that already have different programmes for different service users groups based on their functionality, could implement more or all 6 programme levels from the start.

Category 2: Suitably regulated

This category was formed from two sub-categories, namely:

Sub-category 1: Uniform services with minimum standards

Sub-category 2: On-going monitoring and evaluation of services

Sub-category 1: Uniform services with minimum standards

It was agreed that the SAFMH framework should offer uniform services that meet minimum standards, as evident in the quotes below:

> *"We want to offer a uniform programme. It would be like a franchise like Kentucky [KFC] where we know how the food will taste before we buy it because it is the same at all Kentucky's. They have to meet the same quality standards. Our service users need to know that the workshop in Gauteng offers the same service as the one in Cape Town because it is the same brand and meets the same standards." (CR3)*

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"Each workshop cannot do their own thing any longer; there are minimum standards that we are setting. If they [the SAFMH Directors and PWs] buy in on it [the new model], then they have to buy in on the minimum standards as well." (CR2)

The need for minimum standards was discussed for each programme level in the framework, but it was agreed that these would have to be documented in more detail and were beyond the scope of this study.

Sub-category 2: On-going monitoring and evaluation of services

It was agreed that the Central Hub would be responsible for monitoring and evaluation to ensure compliance with the minimum standards set, as indicated in the quotes below:

"And then the monitoring and evaluation needs to kick in immediately [at the point of implementation] so that there could be no way that that person or that workshop cannot function at the level that we expect them to." (CR3)

"The monitoring and evaluation will have repercussions. That is the job of the hub. They have to ensure quality." (CR2)

"The hub will have to ensure that the standards are met through on-going regular quality assurance monitoring and evaluation. They will have to visit the workshops and check if everything is in place and put corrective steps in place as necessary." (CR3)

Category 3: Sufficiently capacitated

This category was formed from two sub-categories, namely:

Sub-category 1: Adequately resourced PWs

Sub-category 2: Suitably skilled staff

Sub-category 1: Adequately resourced PWs

The CIG acknowledged that all SAFMH PWs have different levels of capacity and resources due to their location, the size of the Mental Health Society and PW and the number and level of functioning of service users, as illustrated in the quotes below:

"Our workshops are so different. Some are small with only a few people and some have more than 200 service users. Some have large buildings, nice equipment and lots of space while others don't even have a building." (CR4)

"Some mental health societies are larger and can cross-subsidise their workshops when times are tough. The smaller ones will have to close their doors." (CR2)

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"In my workshop the people are lower functioning and cannot work so fast. We do not make much money from the stuff that we sell to buy machines and nice equipment." (CR5)

It was further established (from the presentations by PW managers on the CIG) that there is not parity in the subsidies paid to PWs by DSD in different provinces, as evident in the quote below:

"As we now see, the subsidies differ greatly from province to province. Your workshops get almost double the amount per service user than what we get, while his workshops get no subsidy at all. How can we get different subsidies for the same service?" (CR2)

It was further agreed that the current subsidies were not sufficient and aligned with the initial intention when organisations were asked to start up PWs, as shown in the following quote:

"In the circular that DSD sent out in 1970 to inform organisations that funding was available to start PWs for persons with disabilities, they stated that a subsidy will be paid to cover up to 70% of the running costs of the workshops. That subsidy did not keep up with inflation and, in our case; it currently does not even cover 30% of our running costs." (CR1)

It was further established that the staff members-to-service-user ratios are very high at most PWs as can be seen from the following quotes:

"Staff shortages are a reality [at PWs]." (CR2)

"In some cases one staff member is looking after 40 to 50 service users." (CR5)

It was confirmed that an organisational assessment would be done once a PW had indicated that it would buy into a programme level to determine the resourcing and capacity building requirements. This would be followed by a development phase to assist the PW to reach the requirements as illustrated in the following quotes:

"[It is about] identifying the capacity gaps; we [the members of the CIG] have a general idea of where our workshops are at the moment and we have a good idea where we want them to be, but there will have to be an individual organisational assessment to really know what's needed [by individual PWs to be able to provide the best practice model programmes]." (CR3)

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"We will have to go for a developmental approach at first to get them [poorly resourced PWs] up from where they are now to where we want them to be and allow some time for that." (CR2)

"If it is infrastructure changes, they may need resourcing and funding to bring about the change." (CR3)

It was agreed that the SAFMH Central Hub would take responsibility for the organisational assessment, capacity building and resourcing as part of the implementation strategy.

Sub-category 2: Suitably skilled staff

From discussions and presentations on current practice at SAFMH PWs, it was established that most staff members at SAFMH PWs have a passion for working with persons with ID, but they do not have specialised skills or knowledge about ID and do not provide the necessary structure for the service users at the PWs. This is illustrated in the quotes below:

"They [the PW staff] do what they do with a lot of passion, but they don't really know what they are doing [do not follow a programme]." (CR5)

"Sometimes I get the idea that some of the Workshop Staff just don't know where they fit in, because they've never broadened their horizons. They are not exposed to anything else and that's why they carry on the way they are carrying on." (CR5)

"…or staff comes late or there's no real tea time; we drink tea when we're thirsty and we eat when we're hungry." (CR4)

Based on the requirements for implementation of the new SAFMH framework, it was agreed that most SAFMH PWs do not have sufficient or suitably skilled staff to implement the new framework. It was agreed that minimum standards for staffing and staff-service-user ratios are needed, as evident in the quotes below:

"One of the things that we need to realise is: if we want to implement quality and [an] accredited programme, the requirements for the staff will go up." (CR1)

"The current staff at our workshops are not at the level required … they are lacking the necessary expertise necessary for Implementation." (CR3)

"There will have to be minimum standards for staffing and we will have to set the ideal staff-service-user ratio for each level." (CR2)

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The ideal staff-service-user ratio was identified for each level during a discussion of the CIG (based on their experience of managing PW for persons with ID) of what would be appropriate to the South African reality and resources, as can be seen in Table 4.1.

Table 4.1 Ideal staff-to-service-user ratio identified for the programmes in the framework

Level	1	2	3	4	5	6
Ratio Staff : Service users	1:10	1:10-15	1:15-20	1:10	1:10	1:10

It was further agreed that development and retraining of current staff along with the appointment of skilled staff would be needed to meet the criteria for offering quality and on some levels accredited training. This point is illustrated by the quotations below:

"So we are going to retrain our staff; we are going to uplift staff skills, but we will have to also appoint new skilled staff." (CR3)

"If we move into accredited training, the requirements for our staff go up. Then all of our training instructors will have to be accredited to be able to qualify. And we will have to train up assessors and moderators." (CR1)

"It should not just be a person who comes from the community and being a care giver and that's why they ended up in the workshop; it should be someone with technical skills [skills appropriate to the outcomes of each programme level, i.e. a job coach for the supported employment programme]." (CR4)

"We need OT [Occupational Therapy] services." (CR2)

It was agreed that skilled staff (in addition to the PW Manager and required administrative staff) would be needed for the 6 programme levels. The CIG discussed the staffing needs for each programme based on needs of the service users in the group, the activities, the curriculum and training that need to take place and the additional aspects (like marketing, manufacturing) that are needed in each level. They then agreed through negotiated consensus on the staffing needs of each level based on their experience as listed in Table 4.2.

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Table 4.2 Skilled staff required per level of the SAFMH Framework

Level	Group size	Staff required (in addition to the PW Manager and required administrative staff)
1 Higher Care	10	• 2 Training Instructors • Part-time Occupational Therapist (20 hours per week)
2 Life Skills	10-15	• 1 Training Instructor • 1 Assistant Training Instructor
3 Work Skills	15-20	• 1 Training Instructor (Accredited NQF Facilitator) • 1 Assistant Training Instructor • Part-time SETA Liaison and Skills Development Manager • Part-time Sales and Marketing Officer • Assessors and Moderator as needed
4 Bridge to the OLM	10	• 1 Training Instructor (Accredited NQF Facilitator) • Part-time SETA Liaison and Skills Development Manager • Job Coach • Assessors and Moderator as needed
5 Supported Employment	10	• Part-time SETA Liaison and Skills Development • Job Coach
6 Supported Self-Employment	10	• Programme Manager: Entrepreneurial • Job Coach • Part-time SETA Liaison and Skills Development Manager • Sales and Marketing Officer

Category 4: Sustainable in the long term

During a meeting between the CIG and the SAFMH Executive Director, the following was reported by the CIG:

> *"We acknowledge the fact that protective workshops at the moment are pretty much a burden to mental health societies. They are draining some of the resources of the mental health societies. We're not really adding to the income or adding to the profit being made to cross-subsidise other sources. We're going to turn that around so that workshops are really sustainable." (CR1)*

To achieve sustainability the CIG discussed strategies for sustainability relating to subsidies, funding and the need for diverse other income streams. This category therefore consists of two sub-categories, namely:

Sub-category 1: Sufficiently subsidised and funded

Sub-category 2: Sufficient additional and diverse income streams

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Sub-category 1: Sufficiently subsidised and funded

It was agreed that PW would not be able to operate without sufficient government subsidies and corporate / private donors. The CIG agreed that the expectation of DSD for PWs to be less dependent on subsidies by becoming viable business units was not attainable due to the level of functioning of the service users and the burden of care providing services to those service users who are not contributing to production income for the PWs. This realisation is illustrated in the quotes below:

> *"We need the [government] subsidies to operate our workshops." (CR2)*

> *"We do a lot of things that's not acknowledged [covered in the subsidies paid by DSD]: we do development, we do empowerment, we do training, we do skills development and we should get paid for those [as part of a more extensive subsidy by government departments]." (CR1)*

> *"They [Department of Social Development] want protective workshops to be viable business units that are not dependent on subsidies. How can our workshops be viable business units if we have to do the work with people who are not 100%, some not even 50% productive and in need of extensive care? The support we have to provide is not reasonable accommodation. The people who are involved in production at the workshops were all certified as not able to work in the open labour market. They need to understand that we are service providers, not employers or open labour market businesses." (CR1)*

It was agreed that the new framework consists of programmes with outcomes that fall outside of the funding mandate of DSD and calls for inter-departmental responsibility where different levels could be subsidised by different government departments as illustrated in the quote below:

> *"DSD should not have to take full responsibility for all the levels. Level 1 falls in the scope of the Department of Health and Levels 4, 5 and 6 are more aligned to the mandate of the Department of Higher Education, Department of Labour and Department of Trade and Industry. Level 2 should be the responsibility of DSD, but Level 3 could be DSD and Department of Higher Education." (CR3)*

It was suggested that the new framework of best practice be presented to the different government departments for buy-in and that sufficient subsidies be negotiated for activities aligned to their mandates. This decision is reflected in Phase 2 of the proposed implementation strategy (refer to Figure 4.3).

It was further agreed that private funding should be sought to complement the government subsidies. During a session on funding, the potential funding streams were identified for each level as listed in Table 4.3.

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Table 4.3 Potential funding streams identified for each level in the framework

Level	Potential Funding Streams
1 Higher Care	Trusts and Foundations National Lottery Private Sector Companies as part of Corporate Social Investment
2 Life Skills	Trusts and Foundations National Lottery Private Sector Companies as part of Corporate Social Investment
3 Work Skills	Sector Education and Training Authorities (SETAs) National Skills Fund (NSF) Private Sector Companies as part of Enterprise Development Private Sector Companies as part of Corporate Social Investment
4 Bridge to the OLM	Sector Education and Training Authorities (SETAs) National Skills Fund (NSF) Expanded Public Works Programme (EPWP) Disability Development Trust (DDT) Funders focussing on employment integration i.e. Jobs Fund
5 Supported Employment	Sector Education and Training Authorities (SETAs) Disability Employment Concern (DEC) Expanded Public Works Programme (EPWP) Disability Development Trust (DDT) Funders focussing on employment integration i.e. Jobs Fund
6 Supported Self-Employment	Sector Education and Training Authorities (SETAs) Disability Employment Concern (DEC) International funding for small businesses and cooperatives Private Sector Companies as part of Enterprise Development Disability Development Trust (DDT) Funders with a job creation focus

Sub-category 2: Sufficient additional and diverse income streams

In addition to subsidies and funding, the CIG agreed that diverse additional income streams should be explored to ensure the financial sustainability of PWs.

As result of this discussion, the first potential additional income stream was identified to be a monthly attendance fee by service users towards their care, development and training as can be seen in the quote below:

> *"Service users should also contribute towards their training and development. The family do get a disability grant that should be used for the benefit of the service user." (CR1)*

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The second potential additional income stream was identified to be income from sales. This includes income from contract work (that would be done as part of the training in Level 3: Work Skills) and possibly selling the framework and training materials to other non-SAFMH PWs. This is illustrated in the quotes below:

> *"They [the service users in Level 3] still work on your production activities, as their practical experience. So they still work on the contract work and the manufacturing of say bricks and blocks and woodwork items. You are still training them to do that and they still produce the income stream that exists at the moment." (CR2)*

> *"We [SAFMH] would be able to make money from selling the model and training materials to other [non-SAFMH] PWs. In my experience they would rather buy something that was already developed and works well than developing their own from scratch." (CR6)*

A third potential additional income stream was identified to be professional fees charged to employers as recruitment, placement and job coaching fees relating to the placement and support of a person in the open labour market in Level 5: Supported Employment. This is evident in the following quote:

> *"Employers pay personnel agencies recruitment and placement fees to find suitable candidates for their vacancies. In the same way they could pay us a fee for matching the right person with ID to the job." (CR1)*

> *"Job coaching and support in the workplace are reasonable accommodation and it should be paid for by the employer. We could charge the employers a monthly retainer fee for the job coaching and support per employed person with ID we support." (CR2)*

4.4 Summary

During this study a new framework of best practice and implementation strategy were developed for South African Federation for Mental Health PWs (SAFMH PWs) and long-term sustainability strategies suggested. In addition new knowledge of service provision to persons with ID was constructed.

The findings confirmed that the service should be comprehensive in the sense of being inclusive, appropriate, enabling and empowering.

The study further confirmed that the service users with intellectual disability registered at the SAFMH PWs are adults and should be treated accordingly and not as "children for life". It was further confirmed that the service users are not employed by the PWs and would be registered in training programmes in the new framework. To align the training programmes to the abilities and limitations of the service users, the study identified six

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service user groups according to the varying degrees of intellectual disability (ID) and levels of functioning.

The developed framework consists of programmes at six different programme levels to suit the level of functioning of the six service-user groups identified. The six programme levels form a training and career path that is progressive and developmental. It allows service users to progress through the different levels at their own speed and according to their own abilities. The programme levels provide for the care and training needs of persons with ID from stimulation and care, life skills, work skills, bridging to the open labour market, supported employment and supported self-employment. Each programme level has specific training outcomes to prepare the service users for the next programme level. Each programme level includes training on the rights of persons with disabilities and supported self-advocacy opportunities. Service users enter the framework at the programme level aligned to their current level of functioning. The framework also makes provision for suitable levels of support to be provided to service users in all programme levels. Not all service users will necessarily reach level six, because of their varying abilities, limitations and personal preferences, but all service users will progress to their level of maximum potential and/or choice

The findings confirmed that the framework should be systematically implemented, suitably regulated, sufficiently capacitated and have long-term sustainability in a coordinated transformation process.

The implementation strategy developed suggests nine phases, from the first phase of obtaining buy-in by the SAFMH Directors to the last phase where national roll-out takes place. A central SAFMH hub is suggested to coordinate the securing of the needed funding, further development of the framework and materials, obtaining sector buy-in, piloting and roll-out of the framework including quality assurance.

Long-term financial sustainability will be achieved through sufficient government subsidies, sufficient funding and diverse additional income streams including attendance fees, sales of products, services and materials, and professional fees for support provided as part of reasonable accommodation.

In Chapter 5 the findings will be discussed in terms of interpretation, context, implications and limitations of the study, future directions and conclusion.

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Chapter 5 DISCUSSION AND CONCLUSION

5.1 Introduction

The previous chapter stated the findings of the study. It outlined the two themes that emerged relating to comprehensive service provision and coordinated transformation of services. It further informed on the framework of best practice and implementation strategy that was developed as part of this study.

This chapter will provide a discussion of the findings and a conclusion to this study. The research findings and practical implications of this study will be discussed in relation to the findings and the transformation strategy (including the new framework and implementation strategy) that was developed.

The researcher will provide an interpretation of the findings and highlight the practical implications that the developed transformation strategy (including the programme framework and implementation strategy) could have on service delivery. The discussion will explain how the mind-shifts made by the CIG during this study influenced the development of the framework for service delivery. It will explain how the framework could introduce a new paradigm of service delivery to adults with ID. It will further discuss alignment of the programmes and framework with the DSD Policy on PWs.

The researcher argues that PWs need to transform to be significant role-players in the development of adults with ID towards maximum integration into society and that the services offered should empower persons with ID to take up their rightful place as equal citizens. It is argued that this could be achieved through diversified services in a developmental pathway. The researcher further argues that the open labour market is not yet open for equal participation by persons with ID and that this mind-set is hindering the development, progress and integration of persons with ID.

The implications, recommendations and limitations of the study, future directions and recommendations will be discussed as part of the conclusion.

The study was performed within the SAFMH context, drawing on the experience of PW managers and service users of PWs operated by SAFMH mental health societies within the South African context. At the time there was no uniformity in service provision by SAFMH PWs, resulting in a marked difference in service delivery between the well-developed PWs and other less developed workshops. Most PWs offered a single programme despite the wide range in functionality and needs of the service users with ID. Due to very limited post-school opportunities for persons with ID, most service users stayed at the PW for their entire adult lives until they retired or died. Due to insufficient subsidies and funding, most of these workshops reported a lack of sustainability with little or no evidence of transformation towards alignment to the DSD Policy on PWs[19].

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This study was therefore commissioned and funded by the SAFMH to develop a transformation strategy for SAFMH PWs.

5.2 Mind-shifts made by the CIG during this study and the influence these had on the development of the transformation strategy

During this study the CIG members made fundamental mind-shifts that laid the foundation for the construction of new knowledge and the development of the transformation strategy. These mind-shifts related to the status of persons with ID at PWs in that they are adults in training and not employees at the PWs.

Before this study, most of the CIG members perceived adults with ID at their PWs as "children for life" who needed protection and who were not able to make decisions. During this study, CIG members gradually made the mind-shift and realised that their service users are, in fact, adults and should be treated and respected as such. They realised that their service users have the right and potential to make their own decisions with support from staff, aligned to what is described by the American Association on Intellectual and Developmental Disabilities[12]. This realisation changed the way in which the CIG members regarded service delivery to adults with ID, ranging from care and protection to being programmes that would empower and develop service users to take up their rightful place as equal South African citizens in the community and in the workplace. This is aligned to the South African Constitution[26], legislation[3,20,28] and the UNCRPD[13]. The realisation further resulted in the inclusion of self-advocacy training across all programmes in the new framework and the realisation that service users would need support with decision making and in representing persons with ID on different forums. This mind-shift laid the foundation for the new service delivery framework that could become a best practice model in future.

Another mind-shift that CIG members made was that service users were not employed at their PWs, but were in training to learn how to live more independently and gain work experience. It was confirmed that PWs were preparing and supporting those service users who have the potential to find and sustain employment in the open labour market or to set up and run their own ventures. This mind-shift was important for this study since it defined the role of production and manufacturing at the workshops as, firstly, providing training opportunities and, secondly, generating additional income to sustain the PWs. Before the study most of the CIG members had regarded production and manufacturing as the outcome of their PWs and the reason for their existence. This led to frustration and undue pressure as PWs attempted to reach high income targets with a "labour force" of severely disabled "workers" who were not at the required level of productivity to reach such targets.

The realisation that work skills and employment training is only one aspect of service provision to adults with ID is aligned to the legislative[28,29,96] requirements for service delivery to persons with disability. This realisation opened up the CIG discussions to

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include a range of programmes at different levels in the developing framework and with different outcomes for persons with ID with different levels of functional abilities. With this change in thinking from production to development, the CIG realised that the framework would have to provide for the needs of all service users with ID irrespective of their level of productivity but based on their right to services. This is illustrated by the fact that, at the time of the study, only one PW, operated by Cape Mental Health, offered a programme to adults with severe and profound ID in need of higher levels of care. As a result of the mind-shift relating to providing an inclusive service to all adults with ID, irrespective of their level of productivity, a Higher Care Programme was included in the framework at Level 1.

5.3 A new paradigm of service delivery to adults with ID

The findings relating to service provision to adults with ID point to comprehensive service provision in a developmental pathway that enables them to reach their dreams and aspirations. Services that are inclusive, appropriate, enabling and empowering are aligned with the move away from the medical model towards a developmental approach in a social model as supported by the UNCRPD[13], the Integrated National Disability Strategy[28] and the Department of Social Development Policy on PWs[19] and will be discussed further on in this chapter (refer to *Alignment of the newly developed framework* on page 96)

The framework that was developed includes programme levels similar to best practice service programmes found in the literature relating to respite care[42,61,63], skills development[5,15,63] and supported employment[11,44,101]. In contrast to most of those programmes being offered as independent programmes, the new framework suggests that these programmes are offered in a developmental pathway aligned to the model of Cape Mental Health that Terreblanche[34] described.

The framework developed as part of this study could introduce a new paradigm of service delivery to adults with ID across the spectrum of functional abilities (as described in the DSM-5[17]) at SAFMH mental health societies. This could remove the metaphorical ceiling that workshop placement had placed on their development in the past. Until this study, workshop placement and low-level production activities in a non-integrated environment were the only service options for most adults with ID where they remained until they died or retired. The new framework is informed by the principles the CBR Matrix[4] and the VdTMoCA [14] to ensure that service users are included in a holistic programme with opportunities to grow and develop to where some of them may no longer attend the PWs, but receive services provided by the PW on the sites where they may be participants in skills development programmes, in employment or while managing their own ventures. This is a realistic outcome in the South African context with evidence of service users already successfully exiting PWs. This is evident at well-developed PWs like Training Workshops Unlimited (TWU) in Cape Town that is currently

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supporting 75 persons with ID in employment in the open labour market. TWU has started with the development of strategies to support persons with ID in forming co-operatives in future.

Aligned to the CBR Matrix[4], the new framework programmes include the aspects of health, education, livelihood, social and empowerment as is evident in the curriculum of each programme (refer to Appendix F).

Accredited training of persons with ID: The framework is based on the right of persons with ID to lifelong learning. All programmes therefore include training programmes that are aimed at developing the service users with ID to their maximum potential. The researcher is of the opinion that persons with ID should have access to accredited training with training materials suitable to their special educational needs and with appropriate levels of support. The programme framework makes provision for access to accredited skills development opportunities to achieve an NQF-accredited qualification where appropriate. This is envisaged in programme levels 3 (Work Skills) and 4 (Bridge to the OLM) and could be structured in the form of Skills Programmes or Learnerships funded by various Sector Education and Training Authorities (SETAs)[9], such as the programmes already implemented by Cape Mental Health that are being funded by 3 different SETAs.

Persons with ID require special accommodation and extensive support while participating in NQF-accredited training. Even at NQF level 1 (entry level) qualifications, the numeracy and literacy requirements are set at a level that is too high for most persons with ID and prevents them from achieving a qualification such as a cleaner or a gardener at the lowest level available. The training methods and materials are not adapted to the needs of persons with ID and the assessments are not fair in that they test knowledge of the subject by requiring learners to complete a written questionnaire. Accredited training at PWs could lead to persons with ID being able to access post-school qualification opportunities at an integrated learning environment such as a community college.

Employment and income generation training: This component is addressed in all the programmes in the framework besides Level 1. Even though it is not the primary focus in Level 2 (Life skills), the curriculum includes basic work skills training as preparation for progress to the next level (Work Skills). In Level 3 (Work Skills) service users are trained further in the skills and behaviour required to operate within the PW and progress to the next level. In Level 4 (Bridge to the OLM) they are prepared to work in the open labour market, and in Level 5 (Supported Employment) and Level 6 (Supported Self-Employment) they are employed and realised their livelihood aspirations.

In the opinion of the CIG and as described in the Technical Assistance Guide on the Employment of Persons with Disabilities of the Employment Equity Act[20], the support needed by persons with ID in employment and self-employment is a form of reasonable

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accommodation. Aligned with Article 27 of the UNCRPD[13], persons with disability should have access to reasonable accommodation to secure and retain employment in the open labour market. Reasonable accommodation should therefore be negotiated at the point of employment of the person with ID. Since the Employment Equity Act[20] stipulates that the employer should provide and pay for reasonable accommodation, it is the opinion of the CIG that the employer should pay for the services of a job coach. The employer could either employ a job coach or contract with a service provider (like a PW) to provide the service. The latter could be structured as a monthly retainer fee paid to the service provider. From experience the researcher knows that employers who have employed persons with ID and worked closely with a job coach are willing to pay for such a service. Extensive lobbying is still needed to promote the availability of job coaches for persons with ID in the work place. The researcher recommends further awareness campaigns for employers to inform them of the benefits of employing persons with ID with the necessary support by a job coach.

Advocacy training and support: The decision of the CIG to include advocacy training and support in all the programme levels in the framework is important in that self-advocacy training, assisted decision making and self-advocacy support will facilitate access for persons with ID to their right to self-determination. It was clear from the research process that persons with ID can speak for themselves and can influence service delivery. The inclusion of a service user with ID in the CIG offered persons with ID the opportunity to give input and to ensure that the findings are aligned to their rights and needs. The slogan "Nothing about us without us"[58] was honoured in the way the research was administered and service users demonstrated that the slogan held truth.

Besides being in step with the CBR Matrix[4], the findings and framework also supports the tenets of the Vona du Toit Model of Creative Ability (VdT MCA)[14]. The new programme framework could provide hope and motivation, and stimulate service users to dream about reaching new levels of functioning, independence and integration into mainstream society. As described in the VdT MCA[14], this would be achieved by starting at their current level of functioning and providing challenges and higher expectations for development towards their maximum potential. The different programme levels in the pathway could provide opportunities for participation and mastering of skills at their current level of functioning, while at the same time providing challenges to stimulate growth and progression to the next level. Assessments would be developed and introduced at each programme level to monitor progress and to determine readiness to move to the next level. The participants would be allowed to progress at their own speed and according to their own abilities, based on active participation in life experiences and exposure to new challenges.

The persons with ID who formerly had access only to care and basic work skills activities at the PWs could now develop and progress through developmental programmes. Aligned to the support areas identified in the development of the SIS and the I-CAN, the

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new framework makes provision for suitable levels of support to be provided in all the programme levels.

The developed framework therefore provided SAFMH PWs with a template for service provision to adults with ID that is aligned to the level of functioning of the service users with appropriate training methods and materials. The framework could guide the transformation of PWs programmes from a single-programme-to-fit-all to different levels of programmes suitable for service users at different levels of functioning and development.

5.4 The implementation strategy

The implementation strategy is aligned with the criteria for successful transformation, as described in a case study by Oldman et al.[40] based on the transformation of a sheltered workshop in Canada, in terms of the requirement for strong leadership and encouragement that will be provided by the Central SAFMH Hub as part of the central management of the implementation. The Central Hub's taking responsibility for monitoring the outcomes, financial support, consultation with experts and for following a systematic change process are also aligned to Oldman et al.'s[40] requirements for successful transformation.

The central hub that was suggested as part of the implementation strategy and the findings relating to the transformation process will ensure that the implementation and roll-out are coordinated, systematic and regulated, and will allow for the resourcing and capacitating of poorly resourced PWs.

The suggested pilot studies and incremental roll-out that was suggested would further ensure a controlled roll-out process and allow for adaptations to the programmes in the framework, based on the learnings from the piloting process. The suggestion for an organisational capacity assessment and the assessment of the functional levels and support needs of current service users is supported[8,102]. This would assist in determining which programme levels to roll out at each PW, ensure that the current service users are accommodated and supported throughout, and confirm the capacity and the capacity building needs of the organisation before rolling out the programme levels at that organisation.

The implementation strategy could provide for the required resources in terms of staffing and infrastructure to ensure an enabling environment and a more appropriate staff-to-service-user ratio with appropriately qualified and skilled staff including occupational therapists, job coaches and accredited facilitators and assessors where appropriate.

The suggestion by the CIG for uniform services aligned with minimum standards and regulated by the Central Hub could standardise service delivery and provide access to best practice services to all persons with ID across South Africa. Through monitoring and

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evaluation, the Central Hub could introduce corrective measures as needed to ensure quality and prevent exploitation and abuse of service users. Standardisation and uniform service delivery could further ensure that service providers would be able to transfer from one PW to another without interruption to their development and training pathway.

5.5 Increased sustainability

The identified strategies to increase the sustainability of PWs could assist PWs to become more sustainable through diversifying and ensuring sustainable income streams. The need for sufficient subsidies from DSD and other government departments aligned to the outcomes and deliverables of the different programmes in the framework speaks to inter-departmental responsibility for the development of persons with ID. This is aligned to the change from a welfare approach (where DSD subsidised all services for persons with disabilities) to a rights-based and developmental approach with diversified responsibility across relevant government departments as described in the DSD Policy on PWs. In the opinion of the researcher it would be easier to demonstrate alignment of the different programme levels in the framework with the mandates of different government departments than to attempt securing funding for the current PW model as a single programme. With the new framework, different programmes could now be funded by different government departments without the risk of this being perceived as double funding of the same programme by government.

The potential funders identified and aligned to the different programmes in the framework could provide guidance to the Central Hub and individual PWs to identify suitable corporate and private donors for the different programme levels.

The attendance fee suggested to be paid by service users and their families is supported and currently implemented at CMH[5] and could contribute to the sustainability of the PWs. This could further encourage commitment to the training programme by the service user and the family. The attendance fee should be based on a percentage of the disability grant that the service user receives in the form of a monthly Social Security Grant from government[32]. In that way the disability grant will be utilised for the benefit of service users and their development and not, as often seen, for the benefit of other members of the family. The potential challenges with expecting service users to pay an attendance fee are that this could exclude service users who are not able to afford to pay, increase absenteeism from programmes, and lead to the termination of services for those who fall behind with payments.

5.6 Alignment of the newly developed framework to the DSD Policy on PW and the UNCRPD

The new framework for service delivery at SAFMH PWs is supported by the requirements of the Department of Social Development's Policy on PWs (DSD Policy on

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PW) and the United Nations Declaration on the Right of Persons with Disability (UNCRPD).

As required by the DSD Policy on PWs, the framework provides for a person-centred approach which provides programmes at levels suited to the service-users' abilities and limitations with opportunities for progression at their own speed and according to their individual abilities. The pathway formed by the programmes in the framework meets the requirement of being progressive and developmental.

The prevention of the violation of human rights of persons with ID is addressed in all programme levels through training of service users on their rights, training on advocacy skills and support to enable them to speak for themselves, on setting boundaries and requesting help, as well as sexuality education and confirmation that they have the right to say no as recommended by Van der Zande[52]. Persons with ID in the open labour market with the right level of support should be less vulnerable, based on the findings by Brown, Shirage and Kessler[50].

All programme levels promote the maximal level of integration into the community to allow for acceptance, growth and development as described by Wehman, Revell and Brooke[18,44], by virtue of the fact that the SAFMH PWs are community-based facilities, the programmes include training on the use of community resources, and include outings for service users to practise their newly acquired skills in real community settings. Integration into the workplace and attainment of financial independence are addressed in levels 3-6. Each level has programmes that will look at the development of the person, as suggested in the policy.

The need for accurate assessment of service users is addressed in that every level of the framework will have assessment tools for entry and evaluation to exit the level. This accommodates all levels of intellectual disability as described in the DSM-5[17], with the aim of developing the person towards maximal potential and facilitating progression to a higher level of intervention. Each programme level addresses the developmental needs as well as the caring needs of the individual as required by the DSD Policy on PWs[19].

The need for an exit level (as described in the DSD policy on PWs[19]) is addressed by two levels in the SAFMH Framework (viz. levels 5 and 6). Level 5 provides for supported employment and level 6 for supported self-employment. Both these levels cover the need for financial independence highlighted in the DSD Policy on PWs.

The SAFMH Framework developed by the CIG is therefore well aligned to the requirements of the DSD Policy on PWs and the UNCRPD.

In addition, it addresses the shortcomings of the model prescribed in the DSD Policy on PWs[19] that the researcher identified and described in Chapter 1 (refer to page 6). It provides for different programmes at different levels that are appropriate to the needs

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of the service user group for which the programme is intended. In the opinion of the researcher, the phased approach of the implementation, along with the formation of a central hub with a well-defined function, could be the determining factor in the successful roll-out of the framework to all SAFMH PWs.

5.7 Conclusion

The conclusion section will focus on the implications of the findings, recommendations, limitations of the study, future directions for research and dissemination of information on the findings.

5.7.1 Implications of the findings

The findings have multiple implications in terms implementation and the need for a mind-shift by all stakeholders to obtain buy-in. Further implications include change in service delivery to uniform services, staffing, public awareness and sensitisation, costing and funding, increased sustainability, the need for inter-sectorial collaboration and implications for occupational therapy services.

Implications for implementation

The realisation by the CIG that the other stakeholders (including the SAFMH Directors, other PW managers, PW Staff, parents and service users) will need the same mind-shift to ensure buy-in and successful roll-out of the framework has implications for implementation. It means that information will have to be provided and communicated to all stakeholders to allow them the opportunity to re-evaluate and change their perceptions of the potential of adults with ID to progress and develop and their perception on the status of persons with ID as adults and in training at PWs towards higher levels of integration into society. Even though an initial mind-shift is required for buy-in, it is anticipated that it will be an on-going process to change the perceptions of the PW managers, staff, parents and service users.

The need for uniform services across the country according to minimum standards has implications for PWs, the service users with ID and put emphasis on the monitoring and evaluation role of the Central Hub. The PWs would have to strictly adhere to minimum standards enforced by the central hub to ensure that the services offered at all the different PWs are uniform. This will assist service users with ID and their families to find suitable and quality services anywhere in the country and ensure a smooth transition from one PW to another if needed without any interruption in the development of the person with ID. This has implications for uniform branding, standardisation of services and the need for extensive monitoring and evaluation of services similar to a franchise model.

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A further implication would be need for systematic implementation with extensive piloting, organisational capacity assessments and accurate assessment procedures to determine the current level of functioning of service users to ensure appropriate streaming and placement in an initial programme level.

Implications for staffing

The findings suggested that current PW managers and staff may not be suitably skilled to implement the new programme levels in the framework. The implication therefore would be that current PW staff would need to be assessed for potential to be retrained to meet the new requirements for staff. Suitable training courses will have to be developed to meet the skills need in the sector. The new requirements and restructuring of the staffing at PWs may lead to retrenchments or performance capacity evaluations that would have a severe impact on the current staff at PWs. Better qualified PW managers and staff and a more favourable staff to service user ratio should have positive implications for the development of persons with ID at PWs and their ability to progress along a developmental pathway towards integration into society. (Also refer to *Implications for occupational therapy services* discussed later in this chapter on page 32.)

Implications for public awareness, sensitisation and self-advocacy

Since the successful integration of persons with ID into mainstream society and the open labour market is influenced by the perceptions of the public and employers, the findings suggest the need for public awareness, sensitisation and self-advocacy to change perceptions and remove the stigma attached to PWs and persons with ID. It further suggests extensive training and support of self-advocates with ID to speak for themselves.

Implications for inter-sectorial collaboration

As identified by the CIG, the implementation of this new transformation strategy for PWs could not be done by the PWs and the DSD alone. It needs inter-sectorial collaboration between non-government organisations (i.e. SAFMH and mental health societies), government departments (i.e. DSD, Department of Health, Department of Labour, Department of Trade and Industry and the Department of Higher Education and SETAs) and the private sector (companies, trusts and foundations and private donors). It calls for a need for partnerships to ensure that the care and developmental services needed by persons with ID are provided for and that the open labour market could provide employment opportunities and the necessary support to persons with ID.

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Implications for cost, funding and sustainability

The findings of the study have huge cost and funding implications. Programmes will have to be developed aligned to the findings for comprehensive service provision to persons with ID. Most of the SAFMH PWs would need extensive resourcing prior to implementation to be able to offer the programmes in the framework. Additional staff would have to be recruited to meet the staff-service-user ratio identified by the CIG. Higher skilled staff, as prescribed, would be more expensive and would result in increased running costs at PWs. The central hub and its functions would add additional overheads to the SAFMH, including salaries, office administration and travelling costs relating to the implementation at PWs across 9 provinces.

The fact that service users could progress at their own pace according to their abilities and limitations has further cost implications. It could mean that some service users could remain in a particular programme level for a number of years before they are ready to progress to the next level. The programme levels will therefore have to make provision for a number of service users to remain longer in that level and the focus may be on retaining skills and level of independence.

The resourcing of PWs to equip them to deliver the new programme levels will be costly and would have funding implications. Another implication is the need for a formalised relationship for such funding and support by the Central Hub to ensure accountability and clarity on roles and responsibility of the entities.

Implications for occupational therapy services

The findings suggest that occupational therapy services and expertise are needed at PWs. Occupational therapist are trained to assess level of functioning, identify and overcome barriers to integration and assess the need for assistive devices and reasonable accommodation that would be required in the implementation of the new service delivery strategy. Their knowledge and expertise relating to skills development, vocational rehabilitation, supported employment and job coaching are valuable and crucial for the successful development and integration of persons with ID into mainstream society and the open labour market. The implication for occupational therapy services include the need for appropriate undergraduate training and orientation to PWs and service delivery to persons with ID. Information on SAQA, accredited skills development and outcomes based assessment of competency against unit standards (as required by SAQA and the NQF) should form part of the undergraduate training of occupational therapists.

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5.7.2 Recommendations

The recommendations will be discussed as recommendations for implementation, staffing and staff-service-user ratio, public awareness and sensitisation, resourcing, sustainability and inter-sectorial collaboration.

Recommendations for implementation

It is recommended that the SAFMH should follow the implementation strategy as suggested by the CIG by securing initial funding to establish the Central Hub at SAFMH and appoint a hub manager with the necessary skills and experience. The hub should then take responsibility for the further development of the framework, training materials, costing and securing of additional funding for the pilot and roll-out. Successful transformation of the SAFMH PWs will not take place without the dedicated attention, management and regulation by the Central Hub.

It is recommended that current PW managers and staff be provided with the necessary information to enable them to make the required mind-shift to facilitate buy-in into the transformation strategy. This should be arranged by the Central Hub and could take the form of a national road show.

As supported by the CIG and described in the findings, the researcher recommends that the implementation of programmes at individual PWs be determined by an organisational capacity assessment. This would mean that transformation would be aligned with the current status and capacity of each PW. That could mean that some PWs (currently offering only one programme) first transform to offer one or two programmes in the framework, while other PWs (that have already diversified) could choose to start with more programme levels at the outset based on the capacity assessment.

It is further recommended that accurate assessment procedures be developed for the assessment and streaming of service users with ID to ensure that they are placed in the correct programme level to start their developmental pathway. It is recommended that such an assessment be performed by an occupational therapist as it should include components of functionality, barriers to development, the need for assistive devices and reasonable accommodation and the level of support required.

The researcher further recommends that a service level agreement be entered into between the Central Hub and each PW that outlines the relationship between the entities and the roles and responsibilities of each. Such an agreement would ensure that a formal and legally binding agreement is in place to guide the relationship between the entities (since they are separate non-government organisations), set out the key performance indicators and would make provision for arbitration if needed.

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Recommendations for staffing and staff-service-user ratio

It is recommended for PW managers to have knowledge of both business skills and the development of persons with ID to maintain the fine balance between business and development that exists within PWs. At present there is a need for training material for PW managers. It is therefore advised that the Central Hub takes responsibility for the development of a suitable training course and the training of the current PW managers. Retrenchment of current PW managers should be avoided and only used as the last resort in cases were managers are not willing or do not have the potential to be retrained.

It is further recommended that current staff be retrained to offer them the opportunity to retain their employment at the PWs. Retrenchment of current staff should be avoided and used only as the last resort in cases where staff members are not willing or do not have the potential to be retrained.

It is recommended that the group size and staff requirements (ideal staff-service-user ratio and the set of skills required by each programme) identified by the CIG for each level be adhered to during the piloting of programmes in order to confirm if it is the norm and if it would be adequate and appropriate to the service user groups' needs. Failing this, the quality of service provision could be compromised.

In the absence of tailor-made training for job coaches and supporters, the researcher recommends that training be developed by the Central Hub and offered to train sufficient numbers of job coaches and advocacy supporters to deliver the job coaching and support to service users as required and prescribed in the framework.

Recommendations for public awareness and sensitisation

Since successful integration of persons with ID into mainstream society is influenced by the perceptions and attitudes of the mainstream population, it is recommended that extensive public awareness and sensitisation. This could be done as national campaigns by the SAFMH and SAMHAM or at a local level by the staff and service users of each workshop through the printed media, radio, social media or direct contact between service users and the public. This should include awareness raising and information on the rights of persons with ID and their status as equal South African citizens.

It is recommended that self-advocates with ID be provided with the necessary support to speak for themselves. This could start with the establishment of service user committees at the PWs where self-advocates could gain confidence with the support of their peers and supporters. Once they have the courage and confidence, they should be trained and supported to advocate for their rights and integration into society.

The job coaches should acknowledge the important role they play in preparing and sensitising the work environment for persons with ID. It is recommended that the

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Central Hub develop a sensitisation programme for employers, supervisors and fellow staff to be informed of the right of persons with ID to work. Employers must further be informed of the right of persons with ID to a job coach as reasonable accommodation and should ensure that a job coach be available for the person.

Recommendation for resourcing

It is recommended that the Central Hub secure sufficient funding to sufficiently resource each PW for the programme levels identified for implementation. This should be based on the organisational capacity assessment of each PW. It is suggested that the quality of service delivery and the uniformity of service provision would be compromised if resourcing were left up to individual PWs.

Recommendations for increased sustainability and funding

The researcher recommends that the DSD (as the current primary funder of PWs) revise the subsidisation structure for PWs to allow for programme funding instead of the per head subsidy that is currently in place. It is further recommended that the DSD introduce parity in subsidisation by allocating the same subsidy per programme offered by PWs across all the nine provinces of South Africa. It is further recommended that the DSD play a pivotal role in obtaining buy-in from other government departments for the role they should play in supporting and funding the different programme levels that are aligned to their mandate.

It is further recommended that the Central Hub take cognisance of the potential funding streams for each programme level identified by the CIG in securing funding for the implementation. The Central Hub should further explore potential Corporate Social Investment (CSI) funding. Companies could gain points on their BBBEE Scorecards and qualify for deductions from its taxable income when funding designated groups and enterprise development. The Central Hub should form relationships with the CSI Managers that could be fostered into longer term partnerships between SAFMH and corporates that could ensure increased sustainability for the SAFMH PWs. The researcher further recommends that the Central Hub explore additional funding opportunities, including possible international funding opportunities.

Recommendations for inter-sectorial collaboration

The successful implementation of the framework goes beyond just the funding provided by the government departments. These departments should take active responsibility for legislation, policies and programmes that would promote the integration of persons with ID into mainstream society. The researcher recommends that:

- the right to lifelong learning and accredited training be addressed by the Department of Higher Education in the development of future policies relating to

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suitable qualifications, training materials, support and access to an integrated learning environment.

- the Department of Labour provide assistance and incentives to employers when employing persons with ID. This could be in the form of a Supported Employment Grant to employers of persons with disabilities that could cover the cost relating to the services of a job coach and assistive devices that may be required.

Recommendations for occupational therapy services

Besides the part-time occupational therapist recommended for Level 1 (Higher Care), it is recommended that occupational therapy services be available to each workshop to monitor quality assurance in programme delivery and to provide guidance and supervision to the job coaches (if they are not qualified occupational therapists) in Level 4 (Bridge to the OLM), Level 5 (Supported Employment) and Level 6 (supported Self-Employment). Alternatively, in the case of smaller PWs, an occupational therapist could work across a few PWs in an area or occupational therapy services could be negotiated with the Community Based Service Programmes offered by Department of Health in the area.

It is recommended that undergraduate occupational therapy training include information on PWs, the role of occupational therapy services in the development of persons with ID and inform students of the career options at PWs that should be created as an outcome of the implementation of the transformation strategy. It is recommended that modules on skills development, SAQA, the NQF and outcomes based assessment of competencies be included in the undergraduate courses for occupational therapy students to adequately prepare them for their role at PWs in future.

The discussion confirmed that this study had contributed to the research body of knowledge relating to the nature of service delivery and services provided and available to persons with ID in South Africa. In practice this study could lead to the diversification and transformation of services rendered to adults with ID by SAFMH mental health societies (and other service providers) to offer a continuum of services that could develop service users to their maximum potential. The implementation strategy (that includes the formation of a Central Hub to coordinate and regulate the transformation and implementation of services) could assist service providers to transform their PWs successfully and to ensure alignment with the Policy on PWs. This could ensure continued subsidisation by DSD and other government departments and assist to secure additional funding and increase the sustainability of PWs.

This concludes the implications and recommendations. In conclusion of the discussion on the findings, it extended the knowledge on the transformation of service delivery to persons with ID in that they defined the nature of the service to be provided and how

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implementation could take place to ensure successful transformation of service provision.

The findings of this study could transform service delivery at PWs beyond SAFMH across the spectrum of disabilities. The findings on the nature of the service to be provided would be applicable to service provision to all persons with disabilities although the specific programme content and training methods may differ to accommodate the specific needs of the service users. The outline of the framework with the six levels could serve as a template to all PWs to guide them in their transformation process.

The findings on the coordinated transformation of services would be of value to all PWs as guidelines for transformation of services. The implementation strategy that was developed could guide PWs successfully through the transformation process.

The findings fulfilled the SAFMH mandate and expectations for the study. All objectives were achieved and the new framework and implementation strategy adopted in totality by the SAFMH Directors for implementation at SAFMH PWs.

5.7.3 Limitations of the study

Limitations of the study included a lack of knowledge and exposure to other SAFMH PWs and best practice services for adults with ID by most CIG members, the limited time the CIG had due to funding restrictions, and the lack of wider consultation with the sector.

Due to the structure of the SAFMH (where its members are all independent organisations), the CIG members were not colleagues and had very limited interaction with and knowledge of the PWs operated by other mental health societies prior to this study. It therefore required considerable time during the study to understand the services offered at the different PWs and to ensure that all CIG members have a similar frame of reference. During the study this was addressed through presentations and verbal discussions of the different services by the CIG members and the attempts made to align them to the CMH model. Visits by the CIG to a representative sample of SAFMH PWs prior to the first search conference or the rotation of the search conferences to allow for visits to PWs could have assisted to overcome this limitation. It was felt that visits to other SAFMH PWs and specifically the CMH PWs (where some of the programmes included in the new framework are currently implemented) could have enhanced the outcome of the study in that this could have assisted the CIG members to visualise the concept of a pathway of programmes earlier on in the research process. To compensate for this limitation, the researcher used PowerPoint Presentations with photos and showed the CIG the programme calendar, schedules, day routines and management tools. The researcher also brought copies of the programme manuals and work books to the search conferences for the CIG members to review.

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A further limitation was the limited time in which the CIG had to complete the study. Between the first search conference in July 2012 and the presentation to the SAFMH Directors in March 2013, the CIG had only eight months to complete the study and present the findings. The researcher would recommend an 18-24 month period if a study of this nature is undertaken. That would allow for more search conferences with sufficient time between search conferences for the CIG members to reflect on the process and findings away from the CIG-context. It could further potentially have allowed for the development of the training materials and minimum standards as part of the study.

Even though the CIG members were representative of the SAFMH PWs, consultation with the wider PW sector (including staff and service users of PWs operated by other non-SAFMH organisations that offer services to persons with ID) prior and during the study could have added other insights. This was not possible due to the limitations of the funding. For similar studies in future, the researcher recommends focus group interviews with significant role players in the wider PW sector on the service needs of person with ID, including with staff and service users.

5.7.4 Future directions for research

Besides answering the research question, constructing new knowledge on comprehensive service provision to adults with ID, and providing a framework and implementation strategy, this study has also created opportunities for further research.

The new framework and implementation strategy provides an outline and basis for the further development of the programme levels and training materials that could be the topic of a follow-up research study. Other aspects that could be considered for further study to complement this study relate to the development of minimum standards and quality assurance systems, and tracking the piloting and roll-out of the framework.

Once the framework has been implemented, research could be undertaken to obtain and document the service users' perceptions of the new service model, the impact on their quality of life, and determining whether the transformed services could actually led to the successful integration of persons with ID into mainstream society and the open labour market.

The application of the framework as a service option to persons with other forms of disabilities (for example psychiatric, physical, sensory) could be explored and adaptations made to suit the special needs and aspirations of the identified service user groups.

Follow-up studies could be undertaken to evaluate and update the programmes in the framework aligned to the changes in the external environment.

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5.7.5 Dissemination of information on findings

The researcher regards the dissemination of information relating to the findings, including the new knowledge, the new framework of best practice and the implementation strategy, as very important in order to bring about transformation in the PW sector in South Africa.

The framework of best practice and the implementation strategy was presented to the SAFMH Directors in March 2013. Following the SAFMH Directors' Meeting the day after the presentation, the CIG was informed that the SAFMH had adopted the framework of best practice and the implementation strategy in their entirety without any amendments.

The provisional findings were also presented at the World Congress of the World Federation for Mental Health held in Buenos Aires, Argentina, in August 2013 with positive feedback from the audience.

The concept document (describing the framework of best practice and the implementation strategy) was circulated to all 17 SAFMH mental health societies for communication to their staff and service users.

The outline of the framework of best practice and a summary of the different levels were circulated via the Disability Rights communication tree (a South African e-mail database administered by DSD) to inform the sector of the new development.

The researcher further plans to present the findings to different disability forums including the Disability Development Enterprise (DWDE) and the provincial PW managers' forums.

The researcher is also planning to submit 3 research articles on the findings of this study to the South African Occupational Therapy Journal in 2015.

5.8 Summary

The study was successful in achieving the aim and answering the research question. It contributed new knowledge on the nature of comprehensive service provision to persons with ID. It determined that comprehensive services to persons with ID should consist of inclusive, appropriate, enabling and empowering services. Furthermore, services should be available to persons across the full spectrum of ID and allow for development towards the highest level of community integration. Services should be appropriate to the context of PWs, should be oriented to adults and appropriate to their functionality and special needs. They should be developmental and progressive in forming a pathway, offering accredited qualifications where possible and providing for suitable levels of support. Services should further follow a rights-based approach with an advocacy focus to empower persons with ID to take up their rightful place as equal citizens.

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In addition the study provided new knowledge on the coordinated transformation of services through systematic implementation, suitable regulation, sufficient capacity and ensuring that it is sustainable in the long term. Central management was suggested to ensure coordinated implementation. A prerequisite to the buy-in on transformed service delivery by stakeholders would be the mind-shift relating to the status of service users with ID from previously being regarded as employees to being regarded as adults in training towards employment in the open labour market and towards maximum integration into society. Incremental roll-out could allow for pilot studies and gradual transformation and expansion of services. Uniform services with minimum standards could assist to ensure quality service delivery and smooth transition of service users from one PW to another if necessary. Regulatory measures should include on-going monitoring and evaluation resulting in corrective action as needed to maintain quality. PWs should be adequately resourced with suitably skilled staff. To ensure long-term sustainability, these service providers should be sufficiently subsidised and funded through diverse income streams.

This new knowledge informed the development of a new service delivery framework and implementation strategy that could offer persons with ID the opportunity to progress and develop towards their maximal level of integration into society. It further provided PWs with possibilities for conceptualising different models of practice in the form of an implementable framework and a strategy to transform from current status to new best practice status.

The researcher believes that the findings of this study will contribute to a new way of thinking about service delivery to persons with ID and that the study will assist PWs in transforming into significant role players in the development of persons with ID in future.

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APPENDICES

Appendix A: Protective Workshops operated by SAFMH mental health societies

No	Workshop	Location	Service Users	Mental Health (MH) Society
1	Athlone	Cape Town	201	Cape MH
2	Mitchell's Plain	Cape Town	130	
3	Retreat	Cape Town	99	
4	Nonceba	Cape Town	70	
5	Gordonia	Johannesburg	25	Central Gauteng MH
6	Thusananga	Johannesburg	18	
7	Shoshonguve	Shoshonguve	19	Northern Gauteng MH
8	Phutamagole	Mamelodi	15	
9	Aretswaraneng	Atteridgeville	9	
10	Laudium	Pretoria	96	Laudium MH
11	Yonder	Kimberley	297	Northern Cape MH
12	Drostdy PW	Uitenhage	81	Uitenhage MH
13	Sikhulile	Port Elizabeth	40	Port Elizabeth MH
14	Inkqubela 1	Port Elizabeth	55	
15	Inkqubela 2	Port Elizabeth	45	
16	Limpopo PSR	Tzaneen	89	Limpopo MH
17	Chatsworth	Durban	34	Durban and Coastal MH
18	Durban North	Durban	34	
19	Merebank	Durban	110	
20	Newlands	Durban	41	
21	Overport	Overport	32	
22	Phoenix	Phoenix	115	
23	Pinetown	Pinetown	40	
24	Sherwood	Durban	220	
25	Wentworth	Wentworth	74	
26	MH Moosa	Pieter-Maritzburg	146	Pietermaritzburg MH
27	Buxton	Pieter-Maritzburg	100	
28	Inkanyezi	Pieter-Maritzburg	95	
29	Maszakhe	Empangeni	40	Zululand MH
30	Zezithuba	Kwngwanaze	21	
31	Velemseni	Edebe	18	
Total number of service users in SAFMH PWs			2409	

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Appendix B: ID severity levels and adaptive functioning[1,12,17,37,41-43]

Severity Level	Average Adaptive Functioning within the 3 Domains		
	Conceptual	**Social**	**Practical**
Mild (IQ range 50-70)	- Basic literacy - Basic numeracy - Concrete thinking - Struggles with abstract concepts - Able to follow an argument and reasoning - Able to memorise and recall from memory, needs repetition to retain knowledge - Able to understand and follow 3-5 step instructions - Short attention span and easily distractible - Needs more time to learn new tasks - Difficulty with generalising learning	- Decreased judgment and insight - Difficulty linking actions to consequences - Able to learn acceptable social behaviour - Able to manage conversations - Difficulty coping with stress	- Relatively self-sufficient in activities of daily living - Decreased safety awareness, but able to understand and apply basic safety precautions - Able to understand and use technology i.e. cell phones, computer software, basic machinery, driving a vehicle - Able to learn how to use public transport - Able to work as unskilled or semi-skilled workers in the open labour market with support - Difficulty with complex skills like parenting and money management
Moderate IQ range 35-49	- Limited, but useful language skills - At the higher end in this level, the person may be able to develop basic reading, writing and counting skills - Needs easy, concrete language to understand instructions and instructions should be repeated and	- Limited judgment and insight - Able to learn basic acceptable social behaviour with conditioning and repetition - Decreased social inhibition - Decreased frustration toleration if not able to express feelings	- Able to perform basic self-care activities independently with guidance and supervision only - Needs supervision and assistance with road safety and money management - Able to live and function well within a supported living arrangement - Able to perform basic food preparation with

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Severity Level	Average Adaptive Functioning within the 3 Domains		
	Conceptual	Social	Practical
	accompanied by demonstrations - Short attention span and easily distractible - Able to perform 1-2 step instructions - Poor memory and retention of learning - Receptive skills better developed than expression skills - Needs prompting and encouragement to complete tasks		support and assistance - Decreased safety awareness, needs prompting and supervision to apply safety precautions - Able to perform familiar repetitive work tasks but often needs supervision to meet quality, quantity and safety requirements
Severe IQ range 20-34	- Language ability ranges from no language to being able to take part in basic conversation - Often uses gestures to make needs known - May know basic right from wrong - May learn to use alternative augmentative communication - Memory and retention of knowledge better achieved through conditioning	- Limited verbal and expression skills - Inappropriate social behaviour is common including screaming, self-harming, inappropriate sexual behaviour in public	- Often associated with physical disabilities, decreased co-ordination and hand function and epilepsy - Basic self-care with supervision, may be able to feed and undress self, needs assistance with dressing and hygiene activities - Needs on-going / constant supervision and assistance to perform basic tasks, participate in activities and for own safety - May be incontinent or dependent for toilet routines - May need high level structured special care

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Severity Level	Average Adaptive Functioning within the 3 Domains		
	Conceptual	**Social**	**Practical**
Profound IQ Range < 20	- Very basic communication skills - May respond to basic requests - Needs simple 1-2 word instructions - Often needs verbal and physical prompts to follow instructions	- Not able to follow conversations	- Either immobile or very restrictive mobility skills - Limited hand function - Needs physical assistance in activity participation - Unable to meet their own care needs, dependent on caregivers for toileting, feeding and self-care - Most are incontinent and are dependent on carers for hygiene - Visual/hearing impairments and epilepsy are commonly found - In need of high level structured special care

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Appendix C: Sample of Investigator's Declaration for ethical approval

STELLENBOSCH UNIVERSITY

FACULTY OF HEALTH SCIENCES

HEALTH RESEARCH ETHICS COMMITTEE 1 & 2

INVESTIGATOR'S DECLARATION
(To be completed in typescript)

The principal investigator, as well as all sub- & co-investigators must each sign a separate declaration.

A. RESEARCHER

Surname	TERREBLANCHE			Initials	SE	Title	MRS
Capacity	Principal investigator	X	Sub-investigator		Co-investigator		
Department	OCCUPATIONAL THERAPY						
Present position	General Manager, Cape Mental Health			E-mail	santie@cmhs.co.za		
Telephone no.	(w) 021-638 3143	Cell	072 447 0212		Fax	021-637 9642	

B. PROJECT TITLE (MAXIMUM OF 250 CHARACTERS FOR DATABASE PURPOSES)

Developing a best practice model and strategy for the transformation of Protective Workshops affiliated to the South African Federation for Mental Health.

I, (Title, Full name) MRS. SUSAN ELIZABETH TERREBLANCHE declare that

- **I have read through the submitted version of the research protocol and all supporting documents and am satisfied with their contents**
- I am **suitably qualified and experienced** to perform and/or supervise the above research study.
- I agree to conduct or supervise the described study **personally** in accordance with the relevant, current protocol and will only change the protocol after approval by the **HREC**, except when urgently necessary to protect the safety, rights, or welfare of subjects. In such a case, I am aware that I should notify the HREC without delay.
- I agree to timeously report to the HREC **serious adverse events** that may occur in the course of the investigation.
- I agree to maintain **adequate and accurate records** and to make those records available for inspection by the appropriate authorised agents when and if necessary.
- I agree to comply with all other requirements regarding the obligations of clinical investigators and all other pertinent requirements in the Declaration of Helsinki, as well as South African and ICH GCP Guidelines and the Ethical Guidelines of the Department of Health as well as applicable regulations pertaining to health research.
- I agree to comply with all regulatory and monitoring requirements of the HREC.
- I agree that I am conversant with the above **guidelines**.
- I will ensure that every patient (or other involved persons, such as relatives), shall at all times be **treated in a dignified manner and with respect**.
- I will submit all required reports within the stipulated **time frames**.

Principal / ~~Sub- / Co-investigator / Supervisor~~ : **SUSAN ELIZABETH TERREBLANCHE** **(print name)**

Signature: Date: 21 May 2012

CONFLICT OF INTEREST DECLARATION (OBLIGATORY)

I, SUSAN ELIZABETH TERREBLANCHE declare that

[X] I have no **financial or non-financial interests**, which may inappropriately influence me in the conduct of this research study.

OR

[ ] I do have the following financial or other competing interests with respect to this project, which may present a potential conflict of interest: (Please attach a separate detailed statement)

Signature: **Date:** 21 May 2012

HREC Investigator's Declaration: Version no.2, dated March 2008 Page 1

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Appendix D: Information leaflet

PARTICIPANT INFORMATION LEAFLET

TITLE OF THE RESEARCH PROJECT:

Developing a best practice model and strategy for the transformation of Protective Workshops affiliated with the South African Federation for Mental Health.

REFERENCE NUMBER:	S12/05/143
PRINCIPAL INVESTIGATOR:	Santie Terreblanche
ADDRESS:	Cape Mental Health 22 Ivy Street OBSERVATORY 7935
CONTACT NUMBER:	(C) 072 447 0212 (W) 021-638 3143

Responsibilities of participants

Participants are expected to share information and experiences to inform the development of a best practise model and participate within the structures of data collection as structured for this research study.

Termination

This study may be terminated if sufficient funding is not available.

Ethics Committee contact details:

You may contact the Tygerberg Health Science Research Ethics Committee at:

PO Box 19063
Tygerberg 7505
Cape Town South Africa
Tel: 021-938 9677
Fax: 021-931 3352
E-mail: rdsdinfo@sun.ac.za

If you are willing to participate in this study please sign the attached Declaration of Consent and hand it to me before you present or take part in the study.

Yours sincerely

Santie Terreblanche

Principal Investigator

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Dear Participant

My name is Santie Terreblanche and I am the study leader. I would like to invite you to participate in a research project that aims to develop a best practise model and transformation strategy for protective workshops for persons with mental disabilities affiliated with the South African Federation for Mental Health (SAFMH). This study is commissioned and funded by the South African Federation for Mental Health.

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Your consent is hereby sought to participate in this study. Your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

You will **not get any money** for your participation and there are **no direct benefits** to participants. It will **not cost you anything** to participate. If there are any expenses for you to participate, please discuss it with me before you incur the costs to see if a refund would be approved.

This study has been approved by the **Health Research Ethics Committee (HREC)** at Stellenbosch University and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

The study is conducted by a voluntary task team of managers of Protective Workshops affiliated to SAFMH who participates as co-researchers. Service user representatives from the South African Mental Health Advocacy Movement will be designated and co-opted as co-researchers in this process.

The study is an Action Research study with Co-operative Inquiries and will consist of four research conferences during 2012. At these conferences, data will be collected from presentations, visits and focus group interviews. The number of persons that participate will be determined by the persons available with the necessary experience, skills and relevant information.

You will be taking part in a:

- ☐ Presentation (maximum 1 hours)
- ☐ Focus Group Interview (maximum 2 hours)
- ☐ Workshop visit/telephonic interview (maximum 2 hours)
- ☐ Search Conference (2-3 days)

Confidentiality

The research team undertakes to maintain confidentiality in the following ways:

- No single person will be identified to have said or contributed in any way unless they gave written consent for their names to be disclosed where they have made positive contributions to the process that is worthy of credit.
- Documents and transcriptions will be stripped of any identifying information.
- Participants will be given the right to review all documents to confirm that the confidentiality measures described above were adhered to.
- Where data is collected from individuals, a coding system will be used to protect the individual's identity and identifying details kept confidentially by the principle investigator

Please note that the sponsors of the study, study monitors or auditors or the members of the Research Ethics Committee may need to inspect research records.

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Appendix E: Informed Consent Form

Developing a best practice model and strategy for the transformation for Protective Workshops affiliated with the South African Federation for Mental Health.

Declaration by participant

By signing below, I …………………………………..………… agree to take part in a research study entitled **Developing a best practice model and strategy for the transformation for Protective Workshops affiliated with the South African Federation for Mental Health.**

I understand that I will be taking part in a:

- ☐ Presentation (maximum 1 hours)
- ☐ Focus Group Interview (maximum 2 hours)
- ☐ Workshop visit (maximum 2 hours)
- ☐ Search Conference (2-3 days)

On (date)____________________________________ time:___________________________

I declare that:

2. I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
3. I have had a chance to ask questions and all my questions have been adequately answered.
4. I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
5. I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
6. I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…......…….. On (*date*) …………....……….. 2012.

....
Signature of participant

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Appendix F: Summary of programmes in the framework

LEVEL 1: HIGHER CARE	
Group size per section	10
Purpose	To provide a day programme for persons with severe ID in need of higher levels of care to develop to a higher level of functioning
Outcomes	• a structured stimulating day programme provided • their range of life experiences expanded through exposure to a different environments • the participants' cognitive, sensory, motor and social skills developed and maintained through suitable activity participation • an environment provided that offers acceptance and a sense of belonging • respite care provided to prevent burn-out and offer relief to Primary Care Givers • referrals for specialised intervention as needed • special transport provided
Admission Criteria	• 18 years + • In need of higher care to participate in activities like feeding, toileting / diaper changes / adaptation to activities / special transport • Able to participate in a group (not requiring 1:1 attention at all times)
Day Routine	• Full-time programme • Orientation (toilet routine) • Preparation for lunch • Lunch • Cleaning up • Arts & Crafts / games / social activities / sensory stimulation / music /toilet routine • Quiet time (time to oneself)
Curriculum / training	• Sensory stimulation • Life skills • Activities / Arts and crafts • Human Rights and Self-advocacy • Sexuality Education and the right to say no
Staffing (excluding staff shared with other programmes i.e. workshop manager/administrators)	• 2 Training Instructors • Part- time Occupational Therapist (20 hours per week)

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LEVEL 2: LIFE SKILLS	
Group size per section	10 – 15
Purpose	To provide a structured day programme with skills that will assist attendees to be effectively integrated into society and the workplace
Outcomes	• care and supervision needs provided for • a structured day programme offered with self-care, basic work skills and leisure time activities • opportunities created for communication and socialisation • assessments conducted and documented • parent involvement encouraged • number of meetings or training sessions outlined • records maintained • referrals for specialised intervention as needed • acceptable social behaviour encouraged
Admission Criteria	• 18 years + • Confirmed intellectual disability • Daily living skills (independent to take care of the daily living activities) • Developed (fine and gross motor skills) • Able to follow and carry basic instructions • Parent commitment to the programme • Commitment to regular attendance • The person must be motivated • Intake assessment tools (research on the already-existing one); the objective is to look at the level of functioning, not the disability
Day Routine	• Full-time programme • Orientation • Structured programme with slots for self-care, basic work skills and leisure time activities • Training sessions as per the training manual and calendar
Curriculum / possible training materials	The Cape Mental Health model for level 2 was accepted as the curriculum and the training materials. The programme includes a structured day routine with training slots for self-care, basic work skills and leisure time / recreation including Human Rights and Self-advocacy, Sexuality Education and the right to say no.
Staffing (excluding staff shared with other programmes i.e. workshop manager/administrators)	• 1 Training Instructor • 1 Assistant Training Instructor

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LEVEL 3: WORK SKILLS	
Group size per section	15-20
Purpose	To provide an introduction to work, the workplace and the required skills and behaviour to participate in production and/or manufacturing to raise potential and opportunities for employment.
Outcomes	• knowledge of life skills and work skills increased in a protective environment • training and development towards maximum level holistically • increased productivity as per requirements of protective environment • opportunities provided to practise work skills in a protective environment • opportunity to receive an allowance to complement current income • increased safety awareness • increased level of independence • Access to maximum vocational level • Enhanced socialisation and communication skills • Referrals for specialised intervention as needed • acceptable social behaviour encouraged • accredited training offered
Admission Criteria	• 18 years + • The person must meet the criteria for level 3 and should be more functional compared to level 2 • Parents' commitment different from level 1 to level 2 • Commit to regular attendance • Three-year training programme cycle (repeated after three years)
Day Routine	• Full-time programme • It will be close to the protective workshop's routine, but will include training sessions for life skills and accredited training that will be offered • Contract work, manufacturing, enclave teams
Curriculum / training	• Work skills programme • Life skills for preparation for employment • 3-year training programme cycle of accredited training modules • Human Rights and Self-advocacy • Sexuality Education and the right to say no
Staffing (excluding staff shared with other programmes i.e. workshop manager/administrators)	• 1 Training Instructor (Accredited NQF Facilitator) • 1 Assistant Training Instructor • Part-time SETA Liaison and Skills Development Manager • Part-time Sales and Marketing Officer

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LEVEL 4: BRIDGE TO THE OPEN LABOUR MARKET	
Group size per section	10
Purpose	To prepare persons with ID and PD to enter the Open Labour Market (OLM) at an appropriate level.
Outcomes	• Orientation to Bridge programme provided • Career skills training offered towards qualification • Life skills training offered appropriate to cope in OLM (readiness for OLM (CV writing, interview skills, knowledge about Unions, payslips, labour relations disciplinary, basic conduct in the workplace) • Practical placements provided • opportunity to receive a stipend • Job coach / training provider on the job
Admission Criteria	• 18 years + • Interested in working in OLM • Good records concerning attendance, habits and behaviour • Work on familiar basic with less supervision • Able to follow instruction and abide by rules • Potential to look according to work and quality including speed • Ability to master skills through classroom and workplace training as required, based on special training required for the work
Day Routine	• Full-time programme • Training • Work experience • Prepare tools • Load vehicle • Drive to site • Perform duties • Break for lunch and return to workshop • Cleaning tools/store • Clean self • Go home normal time • Off-site: Report to workplace and sign
Curriculum / possible training materials	• 2-year training programme • Tool use • Life skills • Numeracy /literacy • Rights Work readiness • Accredited Unit Standards • Personnel Development Plan (Goals and objectives), Job Coach, Trainer, Assessor/ Moderator • Human Rights and Self-advocacy • Sexuality Education and the right to say no

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Staffing (excluding staff shared with other programmes i.e. workshop manager/administrators)	• Part-time SETA Liaison and Skills Development Manager • Job Coach

LEVEL 5: SUPPORTED EMPLOYMENT	
Group size per section	10
Purpose	To prepare, place and support the person with ID / PD in OLM to ensure retention
Outcomes	• Link a person with PD or ID who wants to enter OLM to a job opportunity • Prepare the person for that job • Support: interviews, applications, life skills, reasonable accommodation, , lobby for on-going support and reasonable accommodation • Once job has been secured, introduction to specific job requirements (tasks, output, behaviour, day routine • on-going support provided as needed for employed person • gradually reduced contact with the Supported Employee (fade) • Reasonable accommodation (advice and service provided as needed)
Admission Criteria	• 18 years + • Persons with ID and PD to enter OLM / already employed in OLM • Employed in OLM with direct employer-employee relationship. • Unemployed persons should have an identified job lined up for placement and continued support
Day Routine	• As per workplace schedule of activities and service provided as needed
Curriculum / training	• Training manual for employers • Sensitisation pamphlets for co-workers/supervisors • Curriculum for three years • Have assessors and moderators • Human Rights and Self-advocacy • Sexuality Education and the right to say no
Staffing (excluding staff shared with other programmes i.e. workshop manager/administrators)	• Part-time SETA Liaison and Skills Development • Job Coach

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<table>
<tr><th colspan="2">LEVEL 6: SUPPORTED SELF-EMPLOYMENT</th></tr>
<tr><td>Group size per section</td><td>Not applicable</td></tr>
<tr><td>Purpose</td><td>To assist, prepare, mentor persons with intellectual disability in starting and running their own income generation venture</td></tr>
<tr><td>Outcomes</td><td>• Persons with ID and PD informed of options for self-employment / Small Venture Creation (SVC)
• Persons trained/coached/mentored to set up and register SV
• “Owners” of SV assisted to access funding, training and support from government/ funding agencies
• On-going training /coaching and mentoring to owners on running of SV
• mediation between owners / members as needed
• owners/members alerted to aspects that may be beyond their abilities / experience that could be outsourced</td></tr>
<tr><td>Admission Criteria</td><td>• 18 years +
• Persons with intellectual disability /psychiatric disability ready to set up / be part of a small venture / self-employment
• Necessary skills / qualifications
• Basic understanding of business practices
• Able to understand benefits and risks
• Willing to invest up front (goods / money)
• Willing to be mentored / supported</td></tr>
<tr><td>Day Routine</td><td>• As per training or workplace schedule of activities and service provided as needed</td></tr>
<tr><td>Curriculum / training</td><td>• Basic business principles/ models (i.e. co-operatives / SMMEs) legal implications and responsibilities
• Skills specific (Job)
• Marketing/costing/selling/buying
• Basic financial skills
• Conflict management/social skills
• Customer service/ Public Relations
• Admin skills
• Outsourcing
• Stock handling
• Profit sharing/re-investment
• Human Rights and Self-advocacy
• Sexuality Education and the Right to say No</td></tr>
<tr><td>Staffing (excluding staff shared with other programmes i.e. workshop manager/administrators)</td><td>• Programme Manager: Entrepreneurial
• Job Coach
• Part-time SETA Liaison and Skills Development Manager
• Sales and Marketing Officer</td></tr>
</table>

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Appendix G: The six service user groups identified by the CIG

Group 1: Low-functioning group in need of higher levels of care – These are persons with severe or profound ID in need of higher levels of care relating to self-care tasks, mobility, communication and activity participation. This group often has associated physical disabilities. The following quotes illustrate the functionality of the service users in this group:

> *"… some people [with severe and profound ID] can't feed themselves; they can't do their toilet routines, or some of them may even be on diapers." (CR7)*

> *"… they [adults with severe and profound ID] cannot care for themselves; they need higher levels of care; not tube feeding and heart and lung machines as in medical higher care, but higher levels of care and assistance to participate in activities." (CR1)*

> *"… they [adults with severe and profound ID] cannot use public transport, they need special transport with special seats to stabilise them while in the bus." (CR2)*

> *"Some of them can talk, some of them can only make understandable gestures and some of them can pick out a correct answer amongst a multiple choice." (CR1)*

> *"Some [adults with severe and profound ID] have high [muscle] tone and some have low [muscle] tone or those other kinds of associated disabilities we spoke about [autism and cerebral palsy]." (CR2)*

> *"Most of them [adults with severe and profound ID] are in wheelchairs. Some can walk, but need 24-hour supervision and care for their own safety." (CR6)*

Group 2: Low-functioning group in need of close supervision – These are persons with ID in need of a structured day programme with close supervision for safety and activity participation. The following quotes illustrate the functionality of service users in this group:

> *"Most [low-functioning service users with ID] are mobile and can do the self-care activities for themselves, but they need prompting and supervision. If the activity is set up, they would be able to do it, but the quality may not be satisfactory. For example: if the mother selects the clothing and lays it out on the bed, the person with ID will be able to put it on, but may miss some of the buttons or put a shoe on the wrong foot. The mother will have to check and assist if needed." (CR4)*

> *"They [low-functioning service users with ID] have poor perception of time and get disoriented and anxious if they do not know what will happen next. They like things to be predictable and structured. It makes them feel safe and reassured." (CR2)*

> *"They [low-functioning service users with ID] need close supervision all the time for their own safety and the safety of others, because they do not have the insight to know something is dangerous." (CR1)*

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Group 3: Higher functioning group not yet able to work in the open labour market – This group includes persons with ID who have the ability and interest to engage in more formal work activities and skills and have the potential to work safely on familiar tasks under distant supervision. The following quotes illustrate the functionality of the service users in this group:

> *"Some [service users with ID] are more independent and can and want to do structured work activities. They attend the workshop because they are not able to work at the speed or meet the quality required in the open labour market yet." (CR3)*

> *"If they [higher functioning service users] know the task, they can go on without much supervision. Most contracts require manual repetitive tasks. It is when a new contract comes in that they need more time and input to learn new skills and to practice the steps." (CR2)*

> *"They [higher functioning service users] are not able to work under pressure or their behaviour is not acceptable in the open labour market…" (CR5)*

> *"They [higher functioning service users] can operate the machines in the workshop and work safely with tools. The staff member just needs to be around for occasional quality checks and to monitor behaviour." (CR3)*

Group 4: Persons with ID who want to and have the potential to work in the open labour market – This group may be able to work in the open labour market, but are in need of preparation, career skills and exposure to open labour market conditions before they would be employable. The following quotes illustrate the functionality and needs of the service users in this group:

> *"Then you get those [service users with ID] who are higher functioning and have learned work skills and behaviour over the years and are ready to move to a next level, but would need training and support to overcome the gap between the workshop and the open labour market. They are only used to the requirements in the workshop and the open labour market is a different ball game." (CR3)*

> *"They only know how to behave and work on contracts in the workshop. They are not qualified in any skills to compete for a job. Most of them are illiterate and would not meet the entry requirements for skills programmes offered in mainstream education." (CR2)*

> *"Most of them [service users with ID] live a protected life between the home and the workshop. They do not have experience of interacting with non-disabled persons besides their family members and the staff at the workshop and will not know how to interact in the work place." (CR1)*

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Group 5: Persons with ID employed in the open labour market in need of on-going support – In order for this group to work optimally and retain their jobs, they would need on-going support. The following quote illustrates the functionality and needs of the service users in this group:

> *"Then there are those who have secured a job, but find it very difficult to keep that job without a high level of support. Some of them do not understand the structure of the workplace or the disciplinary procedures or the instructions. They need someone who can assist them to understand the workplace and to support them to keep their job." (CR2)*

Group 6: Persons with ID who have an interest and the ability to start and run their own income generating venture with support – The following quotes illustrate the functionality of the service users in this group:

> *"Then there are also persons [with ID] who were already in employment, or those who are not able to find employment who wants to do their own thing and venture into self-employment." (CR3)*

> *"Some of them would be able to have an own business like a gardening service. If they have the right equipment they would be able to do the work and the customers would be happy. But, due to their low literacy and numeracy levels, they would not be able to do the invoicing and bookkeeping or handle the money coming in or making payments by themselves. They would need support and someone to do all that for them." (CR1)*

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Appendix H: Programmes and aspects in the CMH PW Model suitable for inclusion

The CIG identified the following programmes or aspects in the CMH PW Model suitable for inclusion in the new SAFMH framework of best practice to be developed:

- The higher care programme (called the Eagles Programme in the CMH Model) aimed at persons in need of higher level of care for self-care and activity participation. This was a new concept to all the other CIG members besides the researcher and one service user representative. It was agreed that the programmes offered as part of the new SAFMH model should provide for the needs of all adults with ID. it was accepted that a service delivery gap exist due to the lack of designated care programmes for this service user group and it was therefore accepted by the CIG members that this programme should be included in the new SAFMH framework of best practice.
- The Life Skills Programme that is a full-time structured programme for low and medium functioning adults with intellectual disability. The programme includes training on self-care, basic work skills, leisure time and the use of community resources and services, and prepares trainees to progress to the Work Skills Programme. Training is done according to the Training Manuals, Basic Work Skills modules and Weekly Themes.
- The Work Skills Programme that is a full-time structured training programme for higher functioning adults with ID and aims to develop them to their maximal level of employment through training in life skills and work skills, and through opportunities to practice their skills through sub-contract work and opportunities to work in OLM factories for trial placements. This programme prepares adults with ID to enter the Open Labour Market Preparedness Programme.
- The Open Labour Market (OLM) Preparedness Programme is a full-time bridging programme between Protective and OLM employment and provides skills development according to the outcomes of the NQF level 1 qualifications. This is complemented by job coaching, life skills and OLM preparedness training. The adults with ID gain experience and change perceptions while working in different service placements as volunteers. The placements include working at other non-government organisations and community services such as Police Stations, Libraries, and Community Health Centres in their communities.
- The Job Coaching and follow-up services rendered to employed Adults with ID as part of the CMH Model's OLM Preparedness programme, but as a separate programme in the form of Supported Employment Services. As part of the presentation of the CMH Model, the researcher highlighted that the follow-up services for employed persons were essential for job retention and she regarded it as unethical to place a person with ID in employment without the necessary support for life to ensure job retention and advancement. It was also reported that no designated funding was available for the supported employment services rendered and that it therefore are often not prioritised. The CIG therefore agreed to include this component as a separate programme in the new SAFMH framework of best practice to ensure the necessary priority, funding and resources for this programme.