RUNNING HEAD: CONSUMER AND CARER PARTICIPATION

TOWARDS A DEVELOPMENTAL FRAMEWORK OF CONSUMER AND CARER PARTICIPATION IN CHILD AND ADOLESCENT MENTAL HEALTH

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Abstract

Objective: This paper examines the concept of consumer participation in the context of developmental changes in parent/child relationships and the associated differences in the utilization of child and adolescent mental-health services.

Method: Existing definitions and characteristics of mental-health service delivery for children and young people (i.e., young clients) are examined to answer the question: *Who is the consumer in the context of clinical services for young clients and their parents and does this change with the child or young person’s developmental stage?*

Results: As children, young people and parents utilize services in this area of mental health practice, the roles of consumer and carer need redefinition to accommodate both young clients and parents as consumers, and parents also as carers.

Conclusion: The proposed framework addresses the changing roles of parents and young clients from infancy to early adulthood to guide consumer and carer participation strategies. If child and adolescent mental-health services are to apply a developmental perspective and engage both young clients and parents as “consumers”, they need to address challenges related to the differences in expectations and capacities of young clients and parents, the complexity of dual roles, and strategies to promote meaningful participation.

Key words:

Consumer participation, caregivers, mental-health services, child, adolescent
Numerous policy documents guiding Australian mental-health service delivery are based on the premise that it is beneficial for organisations to actively involve consumers to assist with developing, implementing and evaluating health strategies and programs. Raphael highlighted the need for suitable strategies in order to develop partnerships with children, young people, and their parents and provide quality child and adolescent mental health services. However, to date, consumer participation in the context of child and adolescent mental-health (CAMH) services has received little attention in published literature, where the focus is primarily on either mechanisms for involving consumers or consumer politics within a broader mental-health context. The only published consumer participation literature in this area relates to parent and child consumer satisfaction with service delivery. Several reports in the grey literature describe the development and implementation of programs designed to include the viewpoints of young person consumers of mental-health services and young people and their parents.

In keeping with Australia’s ratification of the United Nations Convention on the Rights of the Child, health, welfare, and youth advocacy groups have promoted the involvement of children and young people in decision-making related to the services received. National and international initiatives specifically endorse children and young people’s consumer participation in mental-health services. In broader initiatives for child and youth participation in health and welfare services, the literature predominantly refers to children and young people over the age of 12, and rarely refers to those under 8 years of age.
However as parents “play a critical role in children and young people’s mental health and in the treatment of mental-health disorders and problems”(p.4) 16, much of the work in CAMH services encompasses support and direct treatment for young clients, their parents and families 17. (For ease of expression we refer to children and young people attending CAMH services as young clients. Similarly, we refer to parents throughout this article, however we recognize that the more inclusive term parent/caregiver more accurately reflects the growing trend of significant others taking parenting roles.)

Typical interventions are young-client focused (e.g., individual therapy/counselling), parent-focused (e.g., parent counselling), parent-child or family-focused (e.g., family therapy) or systems-focused (e.g., school/community liaison).

While the need to involve young clients is unquestioned, and working collaboratively with them remains important 13, we need to consider whether parents are also consumers and not solely carers. Accordingly, consumer participation in mental-health services for children and young people must therefore be conceptualized differently from that in adult services. Existing participation frameworks that focus on adult consumer participation or youth participation fail to recognize the complexity of service delivery where young consumers with mental-health problems are seen predominantly in the context of their families. In this paper we address the issue of exactly who are consumers in CAMH settings and propose a developmental framework for consumer and carer participation for this context.

DEFINING CONSUMERS AND CARERS

Although the consumer has been defined broadly as a person using or potentially using a health service [e.g., 18], the Australian Health Ministers tightly defined a consumer as “a person utilizing, or who has utilized, a mental-health service” (p.25)
In mental-health services consumers frequently address issues beyond their own individual direct care in order to provide the *consumer voice* on services received by both themselves and other consumers\(^4\), which is the focus of this paper. The Australian Health Ministers define a *carer* as “a person whose life is affected by virtue of a close relationship and caring role with a consumer”\(^19\). A *carer* has also been defined as “a person who provides unpaid or paid support, and care [and who is] usually a family member or friend”\(^20\).

Carer and consumer roles are likely to be clearly differentiated for many people with mental-health problems\(^21\); however, they will be influenced by the age of the consumer\(^22\) and may overlap, as in the case of CAMH. The child or young person is typically recognized as the individual with the identified problem who presents for treatment and is defined as the “identified client” for purposes of data collection. If consumer participation frameworks from adult mental-health services were transferred directly to CAMH, it is most likely that only young clients would be recognized as consumers with parents recognized solely as carers. However, as many young clients are treated within family contexts, both young clients and their parents utilize CAMH services. The direct services provided to parents are a key ingredient of child-centred family-focused practice in CAMH services. In some circumstances, the parent can be the only person receiving treatment. Hence, the classification of parents solely as carers can be challenged. In CAMH, parents are *consumers* according to the definition provided in the National Standards for Mental Health Services\(^21\): that is, they make use of, and are significantly affected by the mental-health service. As parents also have personal experiences of living with a child/young person with a mental-health problem and knowing how difficult this can be, they need to be considered separately from the range of stakeholders (e.g., carers; school, child care
or other community agency personnel) who may also receive direct services. While the perspectives and needs of young clients and parents are distinct, and their voices need to be heard separately, both can speak as consumers.

In addition to being consumers, parents can also be designated as “carers” (i.e., stakeholders/ people responsible for children and young people) in relation to mental-health services. Hence within the CAMH system, parents take on a “dual role” as consumer with regard to the services they receive, and carer with regard to their child who is the “identified client” also receiving services. Whilst this duality (“both the young client and the parent are consumers” and “the parent is both consumer and carer”) may occur in other areas of pediatric care it is particularly characteristic of CAMH services. While carers could possibly be considered consumers in other areas of mental health (e.g., mental-health promotion, dementia intervention), capacity building and illness prevention initiatives are distinct from direct clinical services.

A DEVELOPMENTAL FRAMEWORK FOR PARTICIPATION

As illustrated in Figure 1 we propose a developmental framework for conceptualising consumer and carer participation in CAMH that addresses the age-related stages and changing needs and roles of parents and young clients over time to highlight the “parent-consumer” and “parent-carer” distinction.

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In this developmental framework consumer/carer roles of parents in CAMH are determined by the developmental trajectory of a young client from infancy to adulthood \(^1\), with processes of individuation shaping the interface between “parent and young client as consumer” and “parent as consumer or carer”. Accordingly, there is a reciprocal relationship between the consumer roles of parents and young clients, determined by the young client’s developmental stage. Although the level of parent consumer participation is paramount in early years, it decreases as young clients move into adolescence and early adulthood and take increasing responsibility for their own treatment. The balance between their consumer-roles shifts as the child or young person matures both cognitively and emotionally, is increasingly able to speak on their own behalf, and the focus of treatment changes from family-centred to youth-centred practice. As the young client individuates and establishes supportive relationships with non-familial significant others, their parents carer role also lessens. However, as the developmental trajectories of young clients with mental-health problems may be disrupted and their parents’ continue to participate in family-centred treatment, parents may continue their roles as consumers. Parents are also likely to retain the role of carers and their lives are likely to be affected by their children’s condition to a greater or lesser extent throughout their lives, particularly when their child’s independence and autonomy does not necessarily increase (e.g., autism).

**Challenges**

There are a number of inherent challenges in working within the proposed developmental framework of consumer participation in CAMH where both young clients and parents are recognized as consumers, and parents are seen as both

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\(^1\) Age groups as defined within the National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000: infants 0-2 years, toddlers and preschoolers 2-4 years, children 5-11 years, young people 12-17 years, young adults 18-25 years.
consumers and carers. Overlapping roles can lead to misunderstandings that need to be negotiated by service managers and practitioners, and by parent-consumer representatives themselves. In addition to implementing appropriate organisational structures and participation strategies that support listening and responding to consumer perspectives, managers and practitioners need to attend to “process” issues concerning how these structures and strategies are introduced and maintained over time.

As one of the principal enablers of consumer participation is “organisational readiness” 27, it is crucial for management and practitioners to promote an environment that is accepting of participation by both young clients and parents. Taking the time to prepare the service for the involvement of both consumer groups creates a “consumer-friendly culture” and enhances the likelihood of full and meaningful consumer participation by both young clients and parents. Staff who work with separate groups of consumers need to be sensitive to the complexity of the duality encountered, and orientation and training is likely to help them support and encourage consumer input.

Taking on a dual-role means parent representatives will have to provide perspectives from either, or both, the consumer and carer viewpoints depending on the issue. At different times they will need to participate as consumer representative or carer representatives within the CAMH service and in external mental health working groups. Their contributions as consumer representatives may be challenged by mental-health groups that are primarily tailored for consumers in adult services where clients’ parents are traditionally viewed solely as carers. Parent representatives need to address the challenge of balancing these two roles with the necessary mentoring
and support to be able to maintain a clear distinction between their roles. This will be particularly important during times when their own children face crises.

CAMH services and mental-health groups will need to attend to the parent consumer and carer perspectives without valuing and privileging their contributions over those of young client consumers. Organisations and parent consumers will need to recognize and value children’s and young people’s voices and to ensure they are empowered to the fullest level at which they can participate. It is likely that young clients’ and parents’ viewpoints (e.g., experiences of care, appreciation of how needs should be best met) will be influenced by whether they themselves were instrumental in seeking treatment or are more actively involved in treatment. All parties will have to deal with difficulties that arise when young clients’ and parents’ consumer perspectives and priorities differ. Given the potential vulnerability of children with mental-health problems 28, it may be necessary to empower young clients’ voices for them to be heard if parent consumer perspectives appear to carry more weight. This may be particularly important when parents are involved as consumer representatives over a longer period of time compared with young clients. It is likely that some parents will continue to be involved as consumers and influence CAMH services over an extended period beyond receiving clinical services; whereas, participation by young clients is more likely to be time-limited according to their clinical involvement.

Mental-health groups and CAMH services will need to develop separate policies for the participation of children and young people and parents. There is likely to be common ground between policies reported in two bodies of relevant literature (youth participation and advocacy; health/mental-health consumer and carer participation); however, services will need to develop an integrated participatory framework that supports the roles of both groups within a developmental paradigm.
Implementing the developmental framework requires services to ensure that young clients and parents can actively participate in service planning and evaluation. Are they able make a real contribution to supporting and monitoring direct service delivery, as well as health policy, research and education activities? Effective consumer participation involves more than putting in place structural arrangements and implementing strategies. Without an organisational commitment to funding, training and resources, consumer and carer participation will be no more than rhetoric that fails to influence service quality and the way in which young clients’ and parents’ needs are met. Tokenism is a real risk when organisations strive to satisfy top-down demands to implement consumer participation without necessarily attending to the organisational culture and structures that support participation and actively engage consumers in decision making that influences services 29.

Consumers report some of the difficulties they encounter, including those arising from differing perspectives of organisations and consumers, limited capacity of the organisation to respond to consumer perspectives, and insufficient organisational commitment to providing infrastructure and training 4 30-32. Keeping young clients and parents involved requires that organizations demonstrate that they value, listen, and respond appropriately to consumer- and carer-voices. Sufficient rewards and benefits for young clients and parents who do participate is critical if organisations are to access unique consumer and carer perspectives over time and improve outcomes for young clients and their families.

CONCLUSIONS

Current mental-health policies require CAMH services to actively involve consumers and carers in determining directions of policies and planning, implementing and
evaluating the services they receive. While some services have instigated consumer and carer participation strategies, many will be aware of the need to develop more comprehensive and integrated approaches to actively involve their clients. A developmental framework for conceptualising young client and parent participation enables organisations to consider the relative contributions and to facilitate input from those who use and are significantly affected by CAMH services.
Figure 1  Developmental Framework of Consumer and Carer Participation for Young Client’s and Their Parents.

Note. The line denoting the extent of consumer participation by young clients and parents refers to their capacity to provide the consumer voice on services received by both themselves and other consumers. It does not relate to the broader notion of participation in treatment.
REFERENCES


