

debates and issues

The Taiwanese Association of Family Caregivers: transformation in the long-term care debate for carers

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Accepting political appointment from the government is a double-edged sword for an advocacy group, which could mean a chance to influence policies or conflicts with other advocacy groups. The Taiwanese Association of Family Caregivers (T AFC) went through such a process of transformation when it was appointed as a member of a formal committee set up by the Taiwanese government in 2009 in order to develop and implement a long term care insurance scheme. We named this process T AFC's awakening because this opportunity served as a catalyst for T AFC to confirm its identity as a representative of carers, speaking solely from the carer's perspective.

key words carers of older people • long-term care • role of the third sector • support for carers

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Introduction and background

Carers are socially marginalised in Taiwan and obliged to care for dependent family members. In part, this stems from powerful cultural expectations linked to Confucian family values; these construct family care as an obligation or duty, rather than a choice. Taiwan's demographic and labour market circumstances have pushed this 'obligation' expectation to its limits. The disjuncture between cultural expectations and demographic demands, linked to an ageing population, has become the driving force behind making the care of older people a public, as opposed to a private, issue. In Taiwan, there are 2,938,579 older people; this represented 12.5% of the total population in 2015 (Department of Statistics, 2016). With a disability prevalence rate of 12.7% among the older population, 80% of whom live with their families (Directorate-General of Budget, 2010), it can be estimated that at least 298,560 family members care for older relatives in Taiwan. It is thought that 60% of family members

care for a disabled older person without formal assistance, while 25% hire a live-in migrant care worker, and 15% use home-care and/or day-care services (Chen, 2016).

The Taiwanese Association of Family Caregivers (TAFC) was established in 1996 with assistance from the League for Persons with Disabilities (LPD) and the Federation for the Welfare of the Elderly (FWE). Its aims are twofold: to advocate on behalf of carers; and to join forces with other national advocacy groups to achieve shared goals. While the government and wider Taiwanese society have paid scant attention to carers' issues, in its initial phase, the TAFC quietly supported carers by encouraging the development of support groups and other initiatives. Until 2009, the chief executive officers (CEOs) of both the LPD and the FWE played active roles as TAFC Board members and influenced its operation, despite the potential for conflict of interest between carers and care recipients. By 2009, the TAFC was a well-established, albeit apolitical, organisation, making few demands on policymakers and government, particularly as compared to established advocacy groups like the LPD and FWE. Until its appointment as a member of the government's Long-Term Care Insurance (LTCI) Committee in 2009, it was, in a sense, a 'silent partner'.

How the Taiwanese Association of Family Caregivers works

From the beginning, the TAFC operated at two levels to formulate its policies. By 2009, it had seven local 'chapters' (or branches), covering one third of the country. At this first level, it adopted a dialectical approach in which all local chapters and the national TAFC staff met annually in a two-day meeting. The original purpose of this was for chapters to get to know each other and to share experiences. As the TAFC became more active in promoting carers' issues, however, its 'annual meeting' (or 'gathering') became a key mechanism for understanding carers' diverse needs and for sharing experiences of innovative programmes. It also played an important role in developing and coordinating the TAFC annual plan.

Under the TAFC's governance arrangements, the annual plan requires the approval of the Board of Directors, TAFC's governing body, which forms its second level of operation. The Board comprises academics, representatives of other advocacy organisations, managers of long-term care (LTC) provider organisations and carers. While the 'annual gathering' is informal and comprised only of carers' groups, the Board is formal and comprised mostly of non-carer members. The difference between the two became problematic when in 2009, the TAFC tried to build consensus for its position on the emerging policy debate in Taiwan on LTC.

The 'awakening' of the Taiwanese Association of Family Caregivers

Involvement in LTC policy has acted as TAFC's 'awakening'. In 2008, the nationalist Kuomintang (KMT) party candidate Ma Ying-Jeou won the presidential election and promised to implement a social insurance scheme¹ as a way of managing growing demand for LTC. The LTCI Committee was established by the central government in 2009 (Nadash and Shih, 2013). The LPD and the FWE both had close ties with the previous Democratic Progressive Party (DPP) government, and had held seats on various governmental committees. The new KMT government wanted to replace the LPD as a representative of welfare (service) users, so it was the TAFC, with its apolitical or non-DPP orientation, which was appointed to this committee. The appointment

presented a dilemma for the TAFC. On the one hand, this was the first time that the association had access to a policymaking platform, so the appointment offered the organisation an opportunity to make carers' issues visible in public discussion and to influence the government's agenda. With an estimated annual budget of NT\$2.75 billion (US\$72 million), the LTCI rapidly, and unsurprisingly, became a contested site for 'needs interpretation' (Fraser, 1989). On the other hand, the fact that the TAFC was appointed to replace the LPD put it in direct conflict with an established advocacy group, whose CEO also served on the TAFC Board.

To ensure that carers' voices were heard in the policy debate on LTCI, the TAFC held a forum in 2009 for its Board members and the staff of all its chapters. At this forum, 19 proposals were passed. They included motions on: supporting LTCI (instead of a tax-funded system) as the financing mechanism for LTC; ensuring carers' rights (by providing a public, universal LTC system); treating carers as potential clients (instead of a 'free resource'); providing cash benefits for carers; requesting carers' involvement in care planning for the cared-for person; and demanding formal support services for carers (Wang, 2011).

Some of these proposals conflicted with positions held by the FWE and the LPD. For example, both the FWE and the LPD favoured a tax-based, rather than a social insurance-based, funding system, and the LPD disagreed with the request for carer involvement in care planning for the cared-for person. These substantive differences of view led the CEOs of the FWE and the LPD to resign from the TAFC Board. The LTCI debate thus brought to the fore key differences between the TAFC and other welfare user groups, in so doing confirming its identity as a representative of, and advocate for, carers.

Policy debate on cash benefits

Another area of tension relates to cash benefits. This issue brought the TAFC into conflict with Taiwan's prominent feminist lobby group, the Awakening Foundation, also a member of the LTCI Committee. Women comprise over 80% of carers of older relatives in Taiwan, so caring is an issue of central concern to the feminist movement. Feminist groups in Taiwan often cite Japan as an example of a country where women's groups have rejected cash benefits in their LTCI scheme. They view cash benefits as reinforcing women's 'care responsibilities', an issue that is challenging in a society where women are seeking to break out of such traditional roles (Campbell and Ikegami, 2003). They also argue that cash benefits will encourage families to hire migrant care workers, thereby reducing job opportunities for local people and undermining the establishment of a formal service system.

In Taiwan, LTC is not well established, and cash benefits are seen as a cheap way of providing care for dependent older people. The Taiwanese government proposed setting cash benefits at 30–40% of the value of in-kind benefits (the services that would otherwise be available), mirroring arrangements in Germany. The TAFC, by contrast, supports cash benefits, believing that they can provide choice and income security for carers and enable them to be treated as 'employees of the state', with some employment rights (eg to regular breaks). The TAFC has also argued, however, that such benefits should be equal in value to in-kind benefits.

One of the TAFC's aims is to challenge the dominant 'obligation discourse' relating to family care. The unhappy history of Taiwan's Carer Allowance for Older

People (CAOP) illustrates how this prevailing discourse, in which carers are seen as unworthy of state financial support, affects carers. CAOP (introduced in 1997) was originally designed as a universal benefit. However, the government soon introduced means testing and limited the CAOP target population to low-income households. Eligibility criteria for CAOP are extremely restrictive: recipients must be 'low-income', in the social assistance system, aged under 65 and have no form of paid employment. Although recipients must be of working age and caring full-time, the level of payment is not intended to ensure minimum living standards or to compensate for loss of income. Instead, it is a symbolic recognition of the carer's situation, set at less than 25% of the legal minimum wage (just NT\$5,000, or US\$138 per month). Furthermore, families receiving CAOP are ineligible for home-care, day-care or respite-care services. CAOP recipients tend to be the poorest carers; many consider care to be a familial obligation and sacrifice their entitlement to LTC services in exchange for this limited payment.

The TAFC argues that the expansion of LTC provides an opportunity to integrate the CAOP into the LTCI payment scheme and to transform it from a residual into a universal benefit for carers by eliminating restrictions and raising its payment level (from the equivalent US\$138 to the level of a home-care worker's average salary of US\$690). To remove the cash benefit option, it argues, is to deny economic support for many women who still adopt tradition caring roles (Wang et al, 2013).

The Taiwanese Association of Family Caregivers' negotiation and advocacy strategy

Ungerson (2000) identified four ways in which carers are conceptualised in cash benefit schemes: as obligated family members, paid volunteers, employees of the state and workers with (usually) a loss of income. The TAFC's goal is to ensure that carers are treated as 'employees of the state' with the same level of pay (and rights) as home-care workers. However, current regulations prohibit the hiring of relatives of frail older people as home-care workers; Taiwan's Civil Code defines care as a 'family responsibility'. For the Awakening Foundation, LTCI can provide alternative options, enabling women to be free of family responsibility and, through paid work, gain financial independence and autonomy. The TAFC's position is that LTCI provides choice and income security for women, who can choose to care, or not, for their older relatives (Neysmith, 1997). By compensating them for lost income, cash benefits provide social recognition for unpaid family care. For the Awakening Foundation, the liberation of women means full employment for them (as in the Scandinavian welfare states), while for TAFC, it means financial support for women who choose to provide family care.

To maintain unity among civil society groups in the Taiwanese government's LTCI Committee, the two organisations tried to reach consensus. Following negotiations with the Awakening Foundation, the TAFC agreed not to support cash benefits, and demanded the removal of the ban on family members becoming home-care workers. This met with further challenge, however, as the FWE then demanded that to be hired as home-care workers, carers must obtain a 'care worker licence'. However, this would disqualify a high proportion of carers, such as carers over age 64 and those with little education, so, in response, the TAFC reverted to its former position of supporting cash benefits.

Cash benefits are notorious in the history of welfare in Taiwan, having been used by candidates for election as a ‘free welfare cheque’ to buy votes. The TAFC realised that to create space for discussion on cash benefits, it needed to deconstruct the stigma of cash benefits as providing ‘cash only’, without appropriate assessment and follow-up services. In other words, the TAFC needed to prove that, with appropriate design, a cash benefit programme could ensure good quality in care provision. On 15 November 2013, it held a conference on cash benefits to discuss a variety of options. Proposed programmes included the model of ‘consumer-directed care’ in which cash benefits can be integrated with services and achieve a balance between service quality and client autonomy. The Awakening Foundation remained resistant, however, and chose not to attend.

The 2013 conference was a learning experience for the TAFC, providing an opportunity to explore the complex and seemingly irresolvable debate on cash versus services, and to engage cooperatively with other key stakeholder groups. Debate on cash benefits continued until the presidential election of 2015, when the DPP regained power and announced that it would not be following the LTCI path, but instead move towards a tax-based system. Although the new government promised to increase sales tax and inheritance tax to raise funds for LTC, this still meant that its estimated annual budget for LTC would shrink from NT\$2.75 billion (US\$72 million) to NT\$0.75 billion (US\$23 million). At the time of writing (2016), the debate is suspended, and LTC funding is set to reduce significantly.

Despite their differences, the TAFC and the Awakening Foundation nevertheless agree that the government should develop a range of policies that, directly and indirectly, target family carers. These include protecting family carers from discrimination in the workplace. Suggested support for working carers includes paid leave, flexible work arrangements, services for older people and the extension of the pension system to cover caregiving responsibilities, or make pension contributions on behalf of employees who need to leave the workplace to provide care. The two organisations have thus achieved consensus on supporting working carers, although they continue to differ on cash benefits for full-time carers.

Support for carers

Although not all its proposals have been accepted, the TAFC has successfully made support services for carers a formal part of Taiwan’s LTC services, along with home-based care, community care and institutional care. ‘Support services for carers’ were included in the Long Term Care Act on 15 May 2015, representing a new era for carers in Taiwan, as citizens demanding support from the state to protect their human rights. The prevailing discourse of family responsibility remains powerful, but new ways of ‘framing’ family care have now entered the public discourse.

The TAFC’s involvement in several key government committees may have arisen for political reasons, putting it in direct conflict with other advocacy groups, but it also led the TAFC on a journey towards finding its own identity and voice. The TAFC has come to hold a unique position on the policy stage. Through the process of debating and negotiating with other welfare groups, it has developed its identity as the national representative group for carers, a population that tends to put the needs of others before their own and who often do not care for themselves. The

seven-year debate on LTC in Taiwan is a story of the TAFC learning to speak for itself and to stand up for carers.

Note

¹ Following Japan and Germany, the LTCI plan is designed as a compulsory social insurance that includes all citizens and provides services and cash benefits to individuals who need assistance and support in their daily functions.

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