

UNPAID CARE WORK: IMPACT RECOMMENDATION REPORT

Impact Luncheon: Held October 24, 2017, YWCA Utah

Participants: Anne Burkholder (YWCA Utah), Renata Forste (BYU), Julie de Azevedo Hanks (therapist, researcher), Danny Harris (AARP), Erin Holmes (BYU), Erin Jemison (YWCA Utah), Susan Madsen (UWLP, UVU), Robbyn Scribner (UWLP, UVU), LaDawn Stoddard (UServeUtah), Becky Utz (University of Utah)

Categories	Current Resources/Strengths	Gaps/Challenges	Potential Interventions
<p>1. Financial incentives and support</p>	<ul style="list-style-type: none"> • Respite and support programs, and waivers to help families pay for those programs, do exist to keep people in home- and community-based services. • Crisis care services. • Meals on Wheels programs and others provide support for family caregivers. Many of these programs depend on volunteers. • Pre-tax flex plans for childcare are becoming more common. • The federal FMLA (Family Medical Leave Act) is an option and does not require the person being cared for to be a legally declared dependent in order for the caregiver to use FMLA leave. • Utah currently has a retirement income tax credit for low and middle-income households. • Utah passed a patient designated caregiver rule last year. This means the patient designates their caregiver and then at discharge, the hospital is required to provide training and information on all aftercare to that caregiver (however, there are no requirements on resources to provide to support the caregiver). 	<ul style="list-style-type: none"> • Family caregivers feel forced to put older loved ones in a skilled nursing facility because they cannot get off the waitlist for in-home care and support. Medicaid will also pay for the facility and not home-based care services. It’s a losing situation for everyone involved – facilities are the most expensive form of care and neither the family nor the person needing care wants to be in that setting. But it is the only type of care for which the family can receive financial support. • Many groups and organizations advocate for more funding from the Legislature, but they are competing against other worthy social services programs. • Caregivers spend a significant amount of their own funds to provide care, especially if it is home-based. There are very few, if any, resources to support them. • There are long wait lists for supportive programs. • Many programs depend on volunteers, and those that do have paid staff are very low paying (minimum wage), which impacts quality and consistency of care. • While pre-tax flex plans can be used for elder care, the person being cared for must be legally designated as a dependent of the caregiver. This is a significant barrier for many families. • At the very least, legal guardianship is 	<ul style="list-style-type: none"> • Explore elder care costs as eligible for flex plans, without requiring that the person be a legal dependent. • Explore a similar tax credit to the Earned Income Tax Credit (EITC) for elder care, again without requiring legal dependence. • Eliminate taxes on social security benefits. • Extend retirement income tax credit for next generation of retirees (current AARP policy priority). This is a highly needed source of tax relief. • When hospitals discharge and provide information to the designated caregiver around what the patient needs, also provide caregiver support resources. Same with pediatricians providing information and resources to parents. • Explore incentives to support “aging-in-place” initiatives that incorporate quality home-based care services. • Continue to explore potential flexibilities in state interpretation of federal Medicaid regulations that might benefit caregivers by benefiting the elders and others they care for.

		<p>usually required for the family to be eligible for any financial assistance.</p> <ul style="list-style-type: none"> • The current retirement income tax credit is phasing out. • Utah is one of only 13 states that taxes social security benefits. AARP and others have advocated for ending this tax, but the Legislature is resistant because it would mean a loss of approximately \$63M to the public education fund (all income tax revenue in Utah is allocated to public education). • Costs associated with caregiving that happens outside of facilities and healthcare systems are not reimbursable categories in insurance policies. • There is a large group of people who need caregiving, but who are not eligible for nursing home or skilled nursing facilities. There are few, if any, options for them in the current healthcare system. 	
2. Technology Infrastructure	<ul style="list-style-type: none"> • Technological changes that allow more remote and flexible work arrangements also support unpaid caregivers. • Utah is one of best states for access to broadband internet, which opens up new technology options. • Advances in “smart homes” allows for remote observation that caregivers can use to check in and ensure safety. • Utah is expanding telehealth opportunities, which also helps caregivers. Medicaid has parity with telehealth services, meaning healthcare services must be covered whether they are in-person or through telehealth. 	<ul style="list-style-type: none"> • Telecommuting in general may be restricting rather than expanding nationally because of the types of jobs that are eligible/convenient for these arrangements. This will put a strain on caregivers. • Private and public employee benefits do not yet all have telehealth parity. 	<ul style="list-style-type: none"> • Ensure that telehealth parity becomes the standard for all insurers. • Develop interventions to train and support caregivers through apps, social media, and other online sources.
3. Creation of economic opportunity	<ul style="list-style-type: none"> • There are increasingly more for-profit businesses that provide adult daycare and other caregiving services. 	<ul style="list-style-type: none"> • Low pay for caregiving services that do exist. • Profit incentive may sometimes cut quality corners 	<ul style="list-style-type: none"> • Need to value care across the board. • Expand respite provision – there are economic/business opportunities in this area. • Explore options for the family member who is providing care to receive payment.

STRATEGIES TO STRENGTHEN WOMEN’S IMPACT IN UTAH

			<ul style="list-style-type: none"> • Ensure quality and safety standards for adult daycare and other caregiving services.
<p>4. Capacity building</p>	<ul style="list-style-type: none"> • Salt Lake County has caregiver classes and support groups (Caregivers 101, Stress Buster class). They are very well attended and gaining in popularity. Different Area Agencies on Aging (AAA) offer these classes and programs. • Caregiver support is being emphasized more – e.g., utahcare.org and Utah Coalition of Caregiver Support. KSL also provides a section in their classifieds that serves as a clearinghouse of information and resources across the state for caregivers (especially re: aging). • There are other respite programs and organizations for caregivers of individuals with disabilities as well. • There are non-profits that provide adult daycare and other caregiving services. • There is financial support to help families access services – Medicaid as well as through waivers called home- and community-based services waivers (not the normal Medicaid coverage). • Social Security benefits can also provide this support. There is a federal program called Senior Companions where seniors help other seniors (volunteer-based). 	<ul style="list-style-type: none"> • Caregivers need respite and assistance. • The programs that provide caregiving in order to assist families have long waiting lists. • Not everyone is eligible for Medicaid-assisted programs, and there are waiting lists for those programs as well. • Social Security benefits process is lengthy and burdensome. • Those with “lower” levels of need fall to the bottom of the wait list. They know they will never rise to the top but there is nowhere else to go so they keep trying. Only if something happens to the caregiver will the person with that “lower” level of disability rise to the top of the waiting list. • There are a lot of families and caregivers that cannot use these services and programs, but still need support to stay in the workforce or be able to maintain care for their loved one. Those caregivers are often women. Hard to track those people and how many/who they are because they cannot access services. • It is time and resource intensive to provide support to caregivers. 	<ul style="list-style-type: none"> • Develop online caregiving classes and support groups. All interventions being developed are through apps, social media, online. • Need resources for men to understand the importance of caregiving.
<p>5. Advocacy and shaping attitudes</p>	<ol style="list-style-type: none"> 6. There is at least cultural “lip service” in Utah that care should be valued because so much emphasis is placed on family life. 7. Cultural/gender norms are shifting; we are seeing men valuing caregiving more. 8. Private companies are part of this shift nationally. There is a Tide campaign called “share the load.” 9. We see the shift even more so in young men’s attitudes. 	<ul style="list-style-type: none"> • There are complex social norms and gender roles at play with these issues. • The cultural valuing of care work is still very gendered. Women may still not feel that they truly have choices when it comes to unpaid care work and paid labor force participation. • Women who do work outside of the home still feel more pressure to be in the primary caregiving role as well. This puts a strain on them, which eventually affects 	<ul style="list-style-type: none"> • Need to increase public awareness about these issues. Reframe caregiving as valuable for the whole family (and therefore valuable for their communities), not a gendered role/issue. • Need resources for men to both understand the importance of caregiving, as well as increase the social acceptance of men providing care. • Focus on workplace culture and attitudes that support taking paid leave and other

		<p>health and well-being.</p> <ul style="list-style-type: none"> • Need to create family-friendly workplaces so that when paid leave and other policies exist, both women and men will actually utilize them. • Legislative attitudes around unpaid care still exist – this is “just what you do” as family, women, etc. There is a sense from some legislators that “we didn’t get help with caregiving; you just deal with it.” Not enough recognition of changing demographics in Utah (aging population). • Even if there is an attitude shift among young men, if they move into spaces that don’t support those shifts, it often moves back to a more traditional stance. 	<p>caregiving options when they are available.</p> <ul style="list-style-type: none"> • Use social media – perhaps an “I share” campaign around men’s involvement in caregiving and household work. Need to help Utah “catch up” with some of the national trends on men and women sharing caregiving and other household work. • Touch points for increasing public awareness – schools, pediatricians, senior centers, and faith communities.
10. Laws, policies, and regulations	<ul style="list-style-type: none"> • As noted above, there are some job protections for some leave (FMLA). • Hiring is getting more competitive so there may be increasing incentive for companies/workplaces to create family-friendly environments and policies. 	<ul style="list-style-type: none"> • Real gap in federal and state laws supporting people staying in the workforce and still being able to provide caregiving to loved ones. • The job-protected leave that is available (FMLA) is still unpaid. Untenable for many working families. • We are behind other states in terms of companies with family-friendly workplace policies. 	<ul style="list-style-type: none"> • Pursue work-family leave policies that provide flexibility for caregivers who want/need to keep their job. • Explore businesses/companies that are being innovative and creating policies/practices to support caregivers. Encourage more strategic thinking around these issues in workplaces. • Create economic/tax incentives for innovative businesses.
11. Research and data	<ul style="list-style-type: none"> • Research is happening in the three areas – childcare, elder care, and care for people with disabilities. • “Valuing the invaluable” research showing economic contributions of unpaid caregivers (mostly elder care). Also, for elderly, long-term score card for states (longtermscorecard.org). • The Caring Economy – caringeconomy.org – looks at unpaid caregiving globally and integrating economic impact into GDP (see it as productive work rather than reproductive). • Researchers at the University of Utah are conducting research on how to best support family caregivers. These efforts 	<ul style="list-style-type: none"> • Research is not combined for all three caregiving areas (childcare, elder care, caring for people with disabilities). • It is an ongoing challenge to get the research to the people who need and can utilize it. As in many areas, it often stays in academia and does not reach the public or get translated into practice for those who can implement it. Huge gap between scholars and practitioners. • Long-term care scorecard most recently ranked Utah 50th (went up to 14th when they changed the measures). 	<ul style="list-style-type: none"> • Researchers partner with organizations to help pilot interventions and make their programs more effective. They need to show outcomes and evidence, so scholars and practitioners need to come together.

STRATEGIES TO STRENGTHEN WOMEN’S IMPACT IN UTAH

	<p>have been supported by grants by National Institute of Health, as well as other foundations.</p> <ul style="list-style-type: none"> • Fatherhood Research and Practice Network (FRPN) – goal of connecting men with practitioners to get more involved in parenting. • Annie E. Casey Foundation Kids Count includes information and outcomes for children. Resource for those caring for children. • The State of the World’s Fathers website is a resource. 		
--	---	--	--

This Impact Recommendation Report was compiled, drafted, and refined by Erin Jemison (Director of Public Policy, YWCA Utah) and Dr. Susan R. Madsen (Orin R. Woodbury Professor of Leadership & Ethics, Woodbury School of Business, Utah Valley University). For questions, contact Dr. Madsen at uwlp@usu.edu. For additional information, see the following websites: Utah Women & Leadership Project (www.utwomen.org) and YWCA Utah (<https://www.ywcautah.org/>).