

Care Jam 2021: Resource Pack

Welcome to the Care Jam 2021 participant resource pack.

Here you will find curated and essential information that explores the complexities, challenges, and opportunities around care.

We will address basic definitions, offer up ideas for narrative arcs, and share tips and tricks around uprooting tropes and representing the diverse perspectives of young caregivers, parents, disabled people, people who receive care, and care activists.

TABLE OF CONTENTS

- INTRODUCTION: WHY ARE WE TALKING ABOUT CARE & GAMES?
- GLOSSARY: TERMS & DEFINITIONS
- STATISTICS: CARE BY THE NUMBERS
- CREATIVE BRIEFS: THEMES TO EXPLORE THROUGH GAMES
- TIPS & TRICKS: REPRESENTATION & DEBUNKING STEREOTYPES
- GAMES MECHANICS: ACCESSIBILITY & PLAYER EXPERIENCE
- INSPIRATIONS: CARE IN MEDIA & POP CULTURE
- MEET THE PARTNERS: ORGANISATIONS BEHIND CARE JAM 2021



INTRODUCTION: WHY ARE WE TALKING ABOUT CARE & GAMES?

Everyone is touched by care at some point in their lives: from working parents to people who are disabled, from migrant care workers to our aging loved ones. The COVID-19 pandemic has only **solidified care as one of the most pressing issues of our time**. In a relatively short period, many people became unpaid caregivers for the first time, meanwhile care workers received unprecedented international recognition as "essential workers."

While conversations about how we care for one another have reached the forefront of global discourse, much remains to be done to challenge cultures that have failed to adequately value and support caregiving, while **changing the story of care and the people who do it**. This work requires challenging harmful stereotypes rooted in racism, sexism, ableism, ageism, and xenophobia, while reimagining care narratives within cultural mediums like games.

Games serve as an immense and unique platform for storytelling and exploring hard-hitting themes like care. With nearly 3 billion players globally, there are endless combinations of mechanics and stories to envisage. A game jam, in particular, offers us the opportunity to test new ideas, while incorporating lived experience. So what will this game jam cover?

CREATIVE BRIEFS: THEMES TO EXPLORE THROUGH GAMES

- 1. Centering the stories and lived experiences of care workers, especially migrants, people of colour and women, as leading protagonists.
- 2. Centering the experiences of anyone who may depend on care, such as people who are disabled or aging, as leading protagonists.
- 3. Building empathy and multidimensional narratives about care, community, and interdependence.
- 4. Challenging harmful stereotypes about caregiving and care work, such as who is expected to provide care and how they deserve to be treated.
- 5. Role-playing difficult conversations and/or trainings about care and care responsibilities.
- 6. Connecting family caregivers and care workers to supportive resources.



GLOSSARY: TERMS & DEFINITIONS

As you embark on the Care Jam journey, you will encounter many terms that shed light on the breadth and diversity of care and caregiving experiences. You will also find notable differences in the language and cultural contexts of the UK and US, where most of the partner organisations are operating. To help you, we have developed a handy glossary and defined some of the most commonly used terms. Where relevant, we provided a distinction between the UK and the US.

Activities of daily living (ADL's): The activities of daily living (ADLs) is a term used to collectively describe fundamental skills that are required to independently care for oneself such as eating, bathing, and mobility. ADL is used as an indicator of a person's need for LTSS or other supports.

Care Infrastructure: From child care to paid leave, to home and community-based services, care is a need shared by all at some point in our lives, and is fundamental to enabling economic activity.

Care worker (also: home care worker): A care worker is a person employed to provide care in various roles and settings, for example, nursing homes or supported living homes. Being a care worker requires skills, knowledge and ongoing professional training. Care workers in the US and the UK often work long, unsocial hours in a shift system and weekends and other free days. Care workers don't only work in a residential setting, but they also work for home care providers, which means they travel and care for people in their homes.

Domestic work: refers to work conducted within the home. Domestic workers are the nannies that take care of our children, the house cleaners that bring order to our home, and the care workers, for seniors and individuals with disabilities, that ensure that our loved ones can live with dignity and independently. Domestic workers are majority women, mostly women of color and immigrant women who often return from work to their own homes that need cleaning, or children and elders that need care.

Disabled or person with disabilities: We take our lead from Rewire News journalist s.e. smith, who <u>writes</u>: "The first phrasing, '**disabled person**,' is an example of what's called "identity-first language," in which the identity is placed before the person, acknowledging that it is a key part of someone's experience. It does not imply that their disability is their entire identity, but rather, that it is entwined with their identity.



You can probably think of a few other examples of identity-first language
—"transgender person" or "Asian woman," for example. By contrast, '**person with disabilities**' uses "person-first language," in which someone's disability is treated as a secondary trait, ostensibly with the goal of focusing on the person and using the theory that people shouldn't be defined or limited by their disabilities.

Family caregiver (also in the UK: carer): Someone who is responsible for the physical, emotional, and often financial support of another person - family member, life partner, friend - who is unable to care for themselves due to illness, injury or disability. The care is almost always provided without pay.

Long-term care: This is shorthand for all kinds of eldercare, supports for people with disabilities, and home and community care. This encompasses the full range of care such as institutional and facility care like nursing homes and assisted living facilities to home and community based services, such as adult day care centers and home care.

Medicaid and Medicare: Medicare is an insurance program in the US. It serves people over 65 primarily, whatever their income; and serves younger disabled people and dialysis patients. Medicaid is an assistance program, and serves low-income people of every age. While Medicare is the largest insurer of health care provided in the last year of life, Medicaid is the nation's largest provider of long-term care services for elderly, chronically ill and disabled people. Medicare coverage tends to focus on short-term care that is medically necessary. Many older people in need of long-term care at home rely on Medicaid.

National Health Service: The National Health Service (NHS) is the publicly funded healthcare system in England, and one of the four National Health Service systems in the United Kingdom. It is the second largest single-payer healthcare system in the world.

Nursing care: This refers to the type of care given to those who have been assessed as requiring care to be delivered by a qualified nurse. Like residential homes, they will offer support, accommodation and meals, but in addition will have specialist expertise on hand to provide additional support and care.

Older adults: Aging is a clinical process, and older adults, or seniors, are usually defined by chronological age, usually 65 years or older. However, the process and those we consider "older adults" varies depending on genetics, life- style, and overall health, often influenced by social determinants of health. Older adults represent an extremely diverse group across gender, ethnicity, race, ability, religion, geography,



orientation, ability, body size, and economic status. Everyone reading this will be an older adult at some point if lucky enough to live such a long life.

Person centered care: Providing a person-centred approach is about focusing care on the needs of the individual. Ensuring that people's preferences, wishes, and values guide clinical decisions and provide respectful and responsive care. Health and wellbeing outcomes need to be co-produced by individuals and members of the workforce working in partnership, with evidence suggesting that this provides better patient outcomes and costs less to health and care systems. Part of this is creation of care plans that are tailored to each individual.

Recipient of care: Anyone can be a recipient of care. When we think of people who receive care, we usually think of older people, and 7 in 10 people over 65 need care at some point in their lives. But many other people need care: people with disabilities also often need care in their homes, and though we don't often think of it as care, children require a lot of care in their early childhood years. People who receive care can also be caregivers themselves.

Residential care: Refers to care home, with or without nursing, for older people or people with disabilities who require 24-hour care. Care homes offer trained staff and an adapted environment suitable for the needs of ill, frail or disabled people.

Sandwich generation caregivers: Impacting at least 11 million Americans, sandwich caregivers represent that generation that so often gets lost in headlines between baby boomers and millennials. A distinctive characteristic of sandwich caregivers is that they are more ethnically diverse, younger, and newer to caregiving. At an average age of 41, these caregivers are about 12 years younger than caregivers without children at home and are frequently from the Gen X and millennial generations.

Women's Work: Due to a workforce made up predominantly of women – mostly immigrant women and women of color – and our society's tendency to devalue work performed by women, organisations like the National Domestic Workers Alliance are transforming the way we view domestic work, from being devalued and underappreciated, to viewing domestic workers as skilled workers with cultural and political power.



STATISTICS: CARE BY THE NUMBERS

FAMILY CAREGIVERS: There are <u>44 million</u> (unpaid) family caregivers in the US caring for an adult (parent, spouse, or another loved one). In the UK, it is estimated that 6.5 million people are caregivers — this is <u>1 in 8 adults</u> supporting a loved one who is older, disabled or seriously ill. This is work that is mostly unpaid and largely falling to women, with many reporting feeling exhausted, isolated and unable to cope.

AGING POPULATION: By 2050, the percentage of the world's population over the age of 65 will <u>double</u>. In the US, <u>90 percent</u> of people prefer to age at home and 70 percent will need some form of long-term care in the near-future. In the UK, it's estimated that <u>65,000</u> additional care jobs would be needed to support the aging population between 2017 and 2035.

CARE INDUSTRY: In the US, home care has been the fastest growing industry, growing at 4.4 percent year over year, with median annual pay around \$17,000 annually. In the UK, 71% of care workers were paid below the Real Living Wage, often times less than supermarket workers (source here and here). More than half of all care workers rely on some form of public assistance and care jobs remain underpaid, undervalued and unprotected.

MARGINALISED WORKFORCE: In the UK, US, and many other countries, the care industry is predominantly made up of women workers, most of whom are from migrant backgrounds and/or communities of colour. In the US, domestic work is rooted in the history of slavery and was built on the centuries-long economic exploitation and social subjugation of Black women. Even today, domestic work is burdened with the legacy of racist exclusions from many of the basic labor protections afforded to other workers. In the UK, these issues have only been exacerbated in the aftermath of Brexit with the UK facing <u>record workforce</u> <u>shortages</u>. Ongoing hostile environment policies against migrants, refugees, asylum seekers, and European Union citizens will continue to affect the care industry.



TIPS & TRICKS: REPRESENTATION & DEBUNKING STEREOTYPES

Spotlighting Domestic Workers: A Guide for Storytellers

Resource for writers, directors, producers, and creators who want to tell accurate and authentic stories of domestic workers – nannies, house cleaners, and home care workers – many of whom are immigrant women and women of color.

Tips for Accurate Representation of Older Adults

Resource on authentically representing "older adults." It includes overrepresented stories, harmful stereotypes, quick facts, glossary of terms, and ideas for better representation.

Tips for Accurate Representation of Women and Girls

Resource on authentically and intersectionally representing all women and girls, include those who are transgender, non-binary, gender expansive, intersex, and cisgender. It includes overrepresented stories, harmful stereotypes, quick facts, glossary of terms, and ideas for better representation.

Factsheet on Caregiving in the United States

Resource on caregiving originally developed for writers in television and film. Includes a list of overrepresented depictions and tropes, as well as ideas for more original and innovative care narratives.

Facts About Carers in the United Kingdom

Resource on carers in the UK, who provide unpaid care by looking after an ill, older or disabled family member, friend or partner. This website includes statistics, demographics and information about the wider societal and economic context. Includes facts and themes related to carers who identify as LGBTQ+, people of colour or disabled. More figures are available at the <u>Carers UK website</u>

Report: When the Clapping Stops: EU Care Workers after Brexit

Report from the Joint Council for the Welfare of Immigrants (JCWI) that explores European Union care workers' awareness, understanding and experiences of the EU Settlement Scheme (new immigration status post-Brexit). The report finds that vulnerable EEA+ citizens, care workers and other key workers – the very people we are relying on to pull us through the COVID crisis – are in real danger of being left behind by the EU Settlement Scheme.



GAMES MECHANICS: ACCESSIBILITY & PLAYER EXPERIENCE

Accessibility has become one of the major shifts underway in the games industry. The AbleGamers Charity, one of the Care Jam 2021 partners, believes that making games more inclusive on the back-end opens up the industry to greater representation on the front-end.

One accessible game design thinking tool developed by the organisation is Accessible Player Experience (APX). As a tool, APX helps developers make more accessible game content, while understanding the barriers that players with disabilities may come across when playing digital games. APX comes with a practitioner course and set of design patterns that serve as inspiration.

Second Channel: APX Design Pattern in Action

The design pattern called Second Channel addresses the barrier that some players experience in being unable or unreliably able to take in information from the game. For instance, your game may have characters that speak and give players hints or instructions through audio dialogue. If a player cannot understand information in this way, then there is a barrier blocking them from experiencing the game. One solution is to present the same information through an additional channel like subtitles, which present the dialogue visually rather than just through audio. Second Channel — and the other design patterns that comprise the APX tool — assist developers in ideating solutions for challenges that players may experience in accessing a game's content.

Learn more about the APX Design Patterns and how to use them at Accessible.Games.



INSPIRATIONS: CARE IN MEDIA & POP CULTURE

FILMS

- Roma: available on Netflix, it features the story of an indigenous domestic worker named Cleo in a black and white Spanish and Mixtec-language film.
- ROCKS: a coming of age film about a Black British teenager, who has to manage with her mother's mental health challenges and care for her little brother. The filmmakers actively involved the young cast of mostly first-time actors in the creative and scriptwriting process.
- <u>The Second Mother</u>: Brazilian comedy-drama about a domestic worker in Sao Paolo working for a wealthy family, and the class tensions that arise when her daughter moves into the house where she works.
- <u>Still Alice</u>: US film about a woman who is diagnosed with early-onset Alzheimer's after her 50th birthday, tackling themes of family caregiving.
- <u>Amour</u>: French film that has been called "one of the greatest films about the confrontation of death and ageing"
- <u>Crip Camp</u>: documentary about the 1970's radical roots of the US disability rights movement, tracing back Camp Jened, a summer camp in New York described as a "loose, free-spirited camp designed for teens with disabilities".

TELEVISION SHOWS & DOCUMENTARY

- Extreme Love: Autism & Dementia: Louis Theroux looks at the pressures placed on relationships by conditions such as autism and dementia, meeting both those diagnosed and the people who love and care for them.
- Help: limited series on UK's Channel 4 that explores the devastating impact of Covid-19 on care homes and care workers.
- <u>It's a Sin</u>: this series on Channel 4 follows 18-year-old flatmates over a decade, from public confusion and AIDS denialism in the early 1980s to outright institutionalisation of homophobia by the Thatcher-led government, and touches on LGBTQ+ life and loss, collective care, solidarity and acts of resistance.
- <u>Grace and Frankie</u>: Netflix series about aging, love and loss, and unlikely friendships, starring Lily Tomlin and Jane Fonda, both actresses in their 80's.
- <u>Village of Dreams</u>: documentary about an extraordinary village in Aberdeenshire. The residents of Newton Dee are a mixture of people with learning disabilities and the people who care for them. Everyone lives communally and works together in the farms, gardens and workshops here.
- <u>A Special School</u>: For the first time, cameras capture the reality of life in Britain's biggest special school. This observational documentary shows what is



possible when boundaries are pushed while educating children and young people with additional learning and physical needs.

GAMES

- <u>That Dragon Cancer</u>: an immersive narrative video game that retells Joel Green's 4-year fight against cancer through poetic, imaginative gameplay
- <u>Bury Me, My Love</u>: interactive mobile phone experience made in collaboration with a Syrian refugee who made the same journey as the protagonist in the game.
- <u>Before I Forget</u>: BAFTA-nominated narrative exploration game that examines a world where memories are constantly fading and jumbled.
- <u>Dot's Game</u>: a single-player, 2D, narrative-driven game that follows a young Black woman in Detroit living in her grandmother's beloved home, as she travels through time to relive key moments in her family's history where race, place, and home collide in difficult choices.
- <u>Kentucky Route Zero</u>: point-and-click adventure game where a diverse cast of characters connects personal struggle to systemic realities of health and workers rights.
- <u>Night in the Woods</u>: through anthropomorphic animal characters, this humorous adventure game normalises mental health struggles, including dissociative identity disorders, anxiety and depression.
- <u>Alma</u>: interactive narrative that captures the tension of work-life balance for healthcare workers.
- The Sims: a strategic life simulation game where "sims" go through every stage of life. While sims age, the game does not include any care options.



MEET THE PARTNERS: ORGANISATIONS BEHIND CARE JAM 2021

Care Jam 2021 is presented by the following partners:

<u>Caring Across Generations</u> is a national movement of families, caregivers, people with disabilities, and aging Americans working to transform the way we care in the US.

<u>Code Coven</u> is an education platform and online accelerator for marginalised communities, including people of colour and gender-nonconforming individuals, who want to work in the gaming industry.

<u>Counterpoint Arts</u> is a leading national organisation in the field of arts, migration and cultural change. Its <u>PopChange</u> initiative explores the power of pop culture for social change through comedy, gaming and TV/film.

<u>National Domestic Workers Alliance</u> is the leading voice for dignity and fairness for millions of domestic workers in the United States.

We are also supported by the following organisations:

<u>The Ablegamers Charity</u> is a non-profit charity organisation that wields the power of gaming to break down the barriers of economic and social isolation for children, adults and veterans with disabilities.

<u>BAME in Games</u> is a grassroots and volunteer-run community dedicated to encouraging and supporting more diverse talent to work in the games industry, from mobile, online and console gaming, to VR, AR, esports, VFX and animation.

<u>Games for Change</u> - Games for Change is a non-profit that empowers game creators and social innovators to drive real-world impact through games and immersive media.

<u>POC in Play</u> works to increase the visibility and representation of people of colour in the games industry, while breaking down barriers to entry. T

<u>Rise-Home Stories</u> is a groundbreaking collaboration between multimedia storytellers and social justice advocates seeking to change our relationship to land, home, and race, by transforming the stories we tell about them.



<u>UKIE and the Raise the Game</u> Diversity Pledge - #RaiseTheGame is designed to inspire meaningful, cultural and behavioural change in all games businesses, companies and organisations - whatever your size and wherever you are in your journey.