

Disparities Faced by Individuals with Mental Health Problems: Tools to Forge Pathways to Change



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Disparities & the Mortality Gap:

***When Chronic Health Conditions,
SMI, SUD & Criminal Justice Collide***



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Precious Beginnings

1974



1975



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Hopes
Dreams
Promises
Possibilities



Late December 1998

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Loaded Genes



*many diagnoses,
yet long-lived*

*the Mortality Gap
hits 4th generation*



*Hope amid
heartache. . .*



**Shining
Moments**

*. . . then
relapses amid
fragmented care*

Gifts Along the Way

- Sincere Empathy
- Providers with a special touch
- Treatment and Medication that bring relief & wellness
- Research that illuminates the unknowns
- Beacons of commitment & professional resolve
- ***Chronic Physical Illness + SMI require Integrated Care***

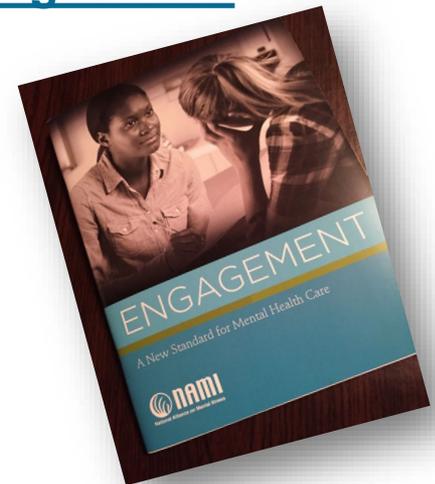


Serious
Illnesses:
complex and
chaotic

Isolation

*stressors
strike individuals,
families,
providers*

- Fragmentation >>> the Rush to Judgment, no context
- **Stand-alone Crisis Care can become its own Revolving Door**
- **Everyone's Education for Integration must start early**
- Policies/people/places/programs for integration must be available
- **Delays, detours, inadequate integration = Mortality Gap**
- **Engagement takes time**
 - Connecting with the person & family
 - Acknowledging the losses
 - Valuing the heroic efforts
 - Rebuilding for resilience



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Watershed Moments

1999

2005

2008

Incarceration

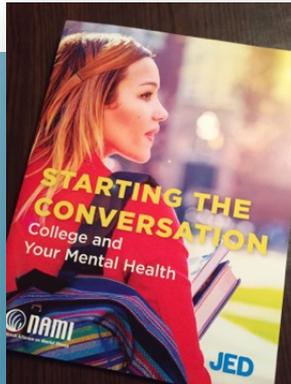
2008-2010

Turning Points without treatment

2010-2012

2013-2016

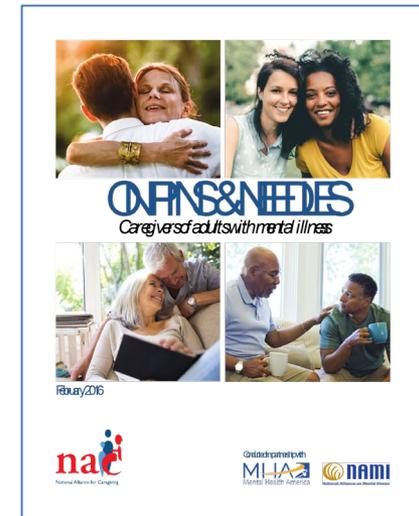




Illness-driven or Person- driven?

Safety Nets
Must Match
Person Needs
for Recovery

- Early identification / FEP
- Coordinated Specialty Care
- Psychiatrists in multiple settings
- Parity Disparity: Addressing complex needs
- Policy, legislation, training must reflect complexities
- Criminal Justice: Jail Diversion, Care & Re-entry issues
- **RECOVERY IS POSSIBLE –There is Help**





*What would
have made the
difference
for our son?*

- **Quality Person-First initiatives must become the Gold Standard in medical training and community settings**
- **REENTRY, RECOVERY and RESILIENCE DON'T HAPPEN IN THE HOSPITAL**
- **Where were Evidence-based Interventions?**
 - only 1 psychiatrist had successfully treated a person with Type 1, SMI and SUD
 - No Dual-Diagnoses Care available in Austin, TX.
- **Psychiatry has a KEY ROLE to play with primary care and other integrated models**
- **Confusion and ignorance abound –where's the Cultural Competence for young adults?**
- **FRAGMENTED SYSTEM COSTS RECOVERY**
- **FRAGMENTED SYSTEM COSTS LIVES**

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More Precious Beginnings

**Genes are
not destiny:**
vulnerable genes, yes . . .

*Effective practices are
within reach*
> *saving money*
> *saving lives*



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The Integrated Generation

*Early identification
intervention
integration*



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Policy+
Research+
Innovation+

*Close
Disparities*

*Advance
Cultural
Competence &
Person-
centered
Recovery*



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Disparities in the world of Caregivers



Report Findings

Report available at:
www.caregiving.org/mentalhealth

The Big Picture

*Data from NAC &
AARP 2015*

- **8.4 million Americans** care for an adult with an emotional or mental health issue*
- Caregivers have typically **provided care for 8.7 years**, while caregivers of an adult care for 4 years on average (any condition).
- Most care recipients (58%) are between 18-39 years; **most caregivers (45%) are parents caring for an adult child**, though other relationships can be impacted
- The main conditions requiring care are **bipolar disorder (25%), schizophrenia (25%), depression (22%), and anxiety (11%)**

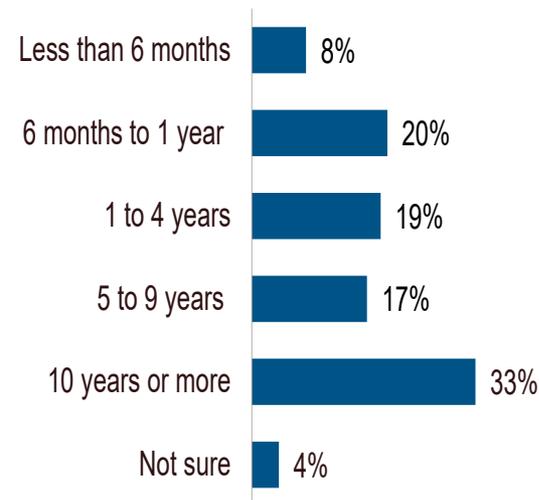
* [Caregiving in the U.S. 2015](#), National Alliance for Caregiving and AARP Public Policy Institute

One-third of caregivers have served as caregivers for 10+ years

Figure 2: Duration of Care

Q14. How long have you been providing/did you provide care to your [relation]?

(n=1,601)



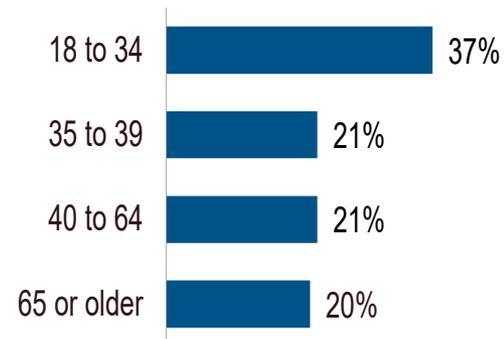
The majority of people receiving care were between 18-39 years old:

*Serious
Implications for
Empowerment
Emancipation &
Recovery*

Figure 5: Care Recipient Age

Q13. How old is/was your [relation]?

(n=1,601)



Critical Disparities compromise us all

- > Shame
- > Isolation
- > Re-entry
- > Recovery

- **Arrest**

About one in three caregivers report their loved one has been arrested (32%)

- **Homelessness**

One in five caregivers report their loved one has been homeless for a month or longer (21%)

- **Self-Harm and Suicide**

Two-thirds of mental health caregivers are concerned their loved one will self-harm (68%) or die by suicide (65%)



Public Policy Solution:

21st Century Cures Act

Educate providers and caregivers about HIPAA and other opportunities

Develop and disseminate model training for providers, lawyers, peers and families, **including family & friendship caregivers**, on appropriate communication of health information

To dignify

To honor and

To support people living with mental illness.

Public Policy Solutions

**Goal: to
Honor and
Emancipate
with peer
support &
activism**

- Provide **assistance for both caregivers and individuals in navigating the mental health system.** County and state providers can help.
- **Include caregivers as part of health care team.**
- **Educate and provide resources** for caregivers, especially with issues of stress & caregiver health.
- **Reduce isolation – Engage community**
- **Identify losses, acknowledge & heal grieving**
- **Remove the shame – Refuse the stigma**
- **Make Mental Health a Community Priority**

Disparities in Care and Caregiving:

Let's shift
these stats to
models that
Empower

- Average age is 46.3 years old but **most are under age 40**
- **Almost half** live in same household as caregiver (45%) or within 20 miles (27%)
- **3 in 10** have an alcohol or substance abuse issue
- **Almost half** are financially dependent on family and friends

Public Policy Solutions

- **Integrate mental health questions into all health care assessments**, and provide regular screenings.
- **Expand opportunities, credentialing, supervision and re-imburement of Peer Support Specialists across the continuum of care**
- **Advocate for treatment parity** for mental health issues equal to that of medical health issues.
- **Ensure access and reimbursement for continuum of care**
- **Advocate for access** to education, accommodations, re-entry in education and effective employment opportunities --including supported employment

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*Do you know what it's like.....?
Intersectionality Diagnosis and Disparity*

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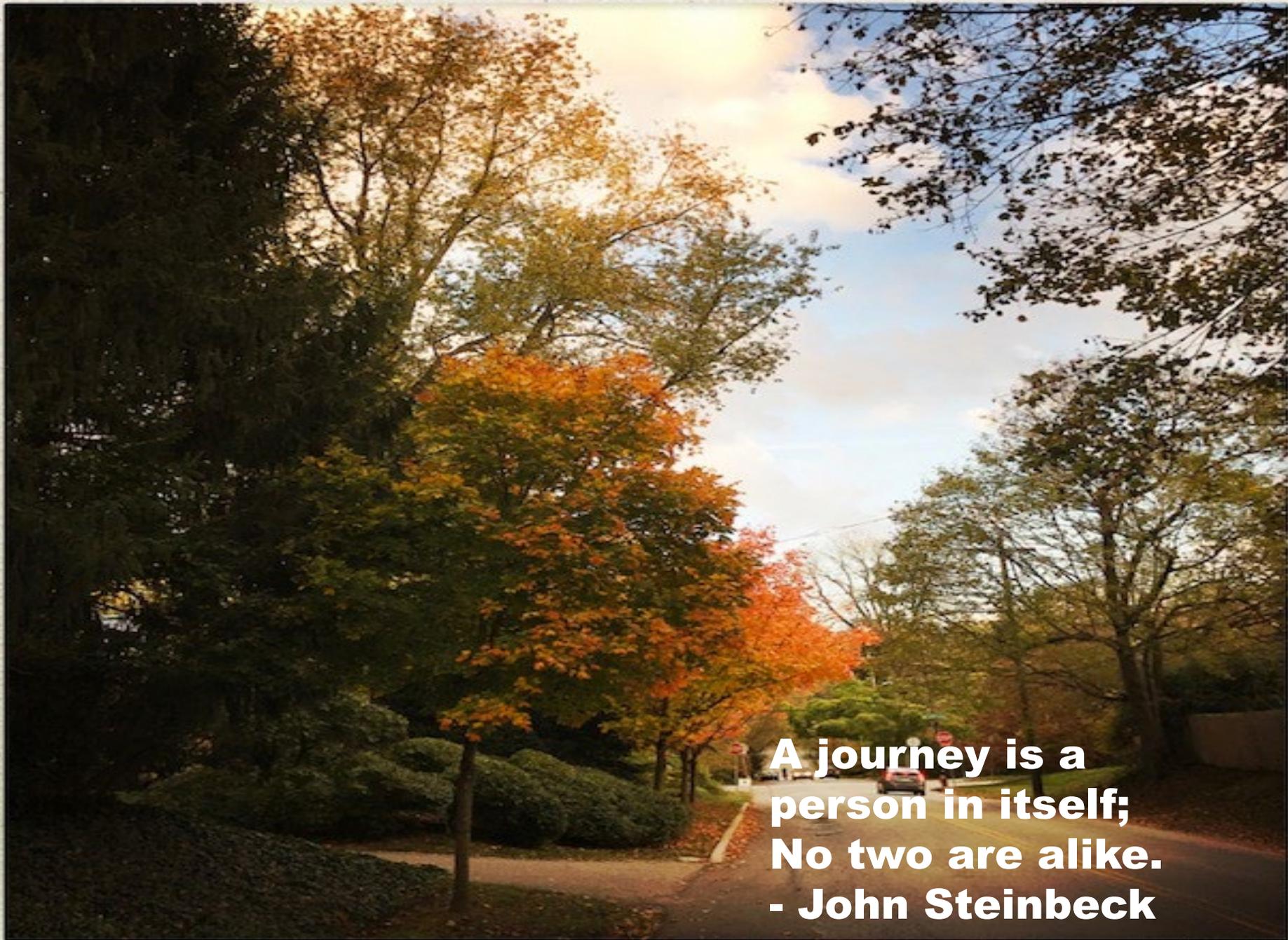
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Disclaimer

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**A journey is a
person in itself;
No two are alike.
- John Steinbeck**

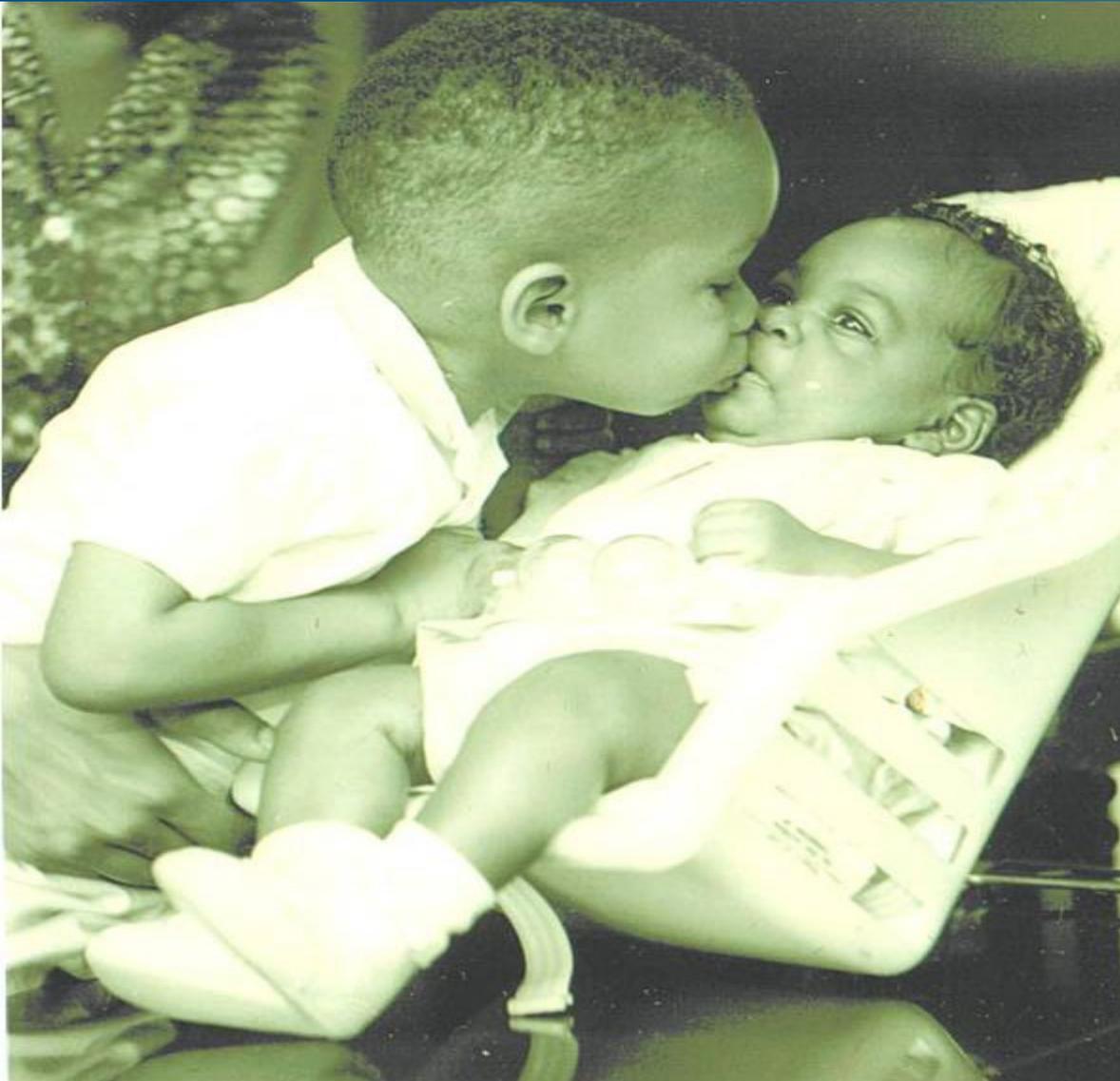


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Sister
Daughter
Grand-Daughter
Cousin

African-American
Muskogee-Creek

ArmyBrat/Global
Nomad

Human
Person

REST ROOMS

WHITE

COLORED



L&N

B&J SIGNS 1929





BOY, I SAY BOY..

FIFTYONEFIFTY

FIFTYONEFIFTY

FIFTYONEFIFTY

**YOU'RE ABOUT TO EXCEED THE
LIMITATIONS OF MY MEDICATION.**

FIFTYONEFIFTY

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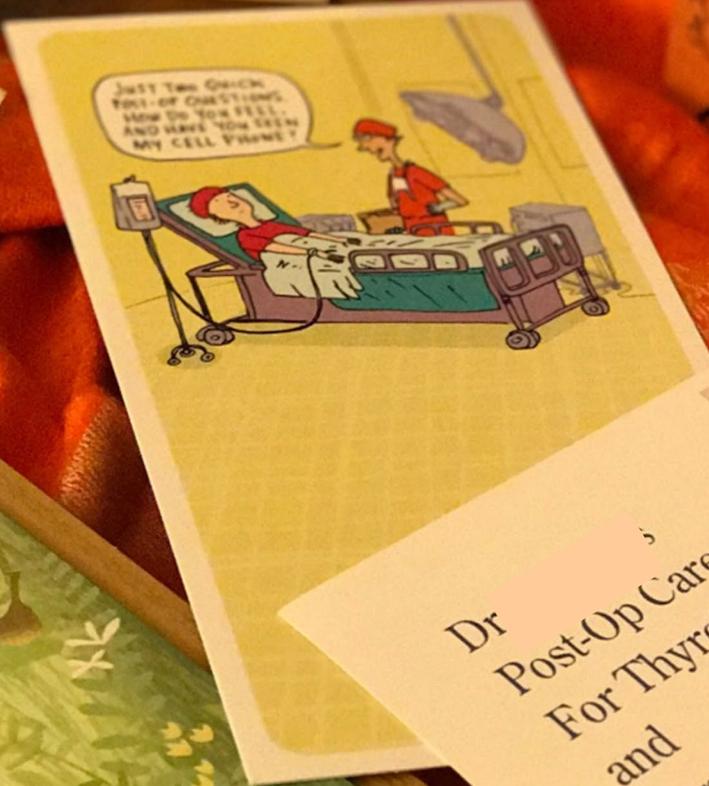
**Analysis | The Health 202:
Patrick Kennedy
shepherded a major
mental-health bill into law.
Ten years later, big barriers
remain.**

[washingtonpost.com](https://www.washingtonpost.com)

Sometimes caring
can touch where
words can't reach.



loved...
when their pain becomes
too much to bear
and we help them
to find rest.



Dr. [Name]
Post-Op Care
For Thyroid
and
Parathyroid
Surgery

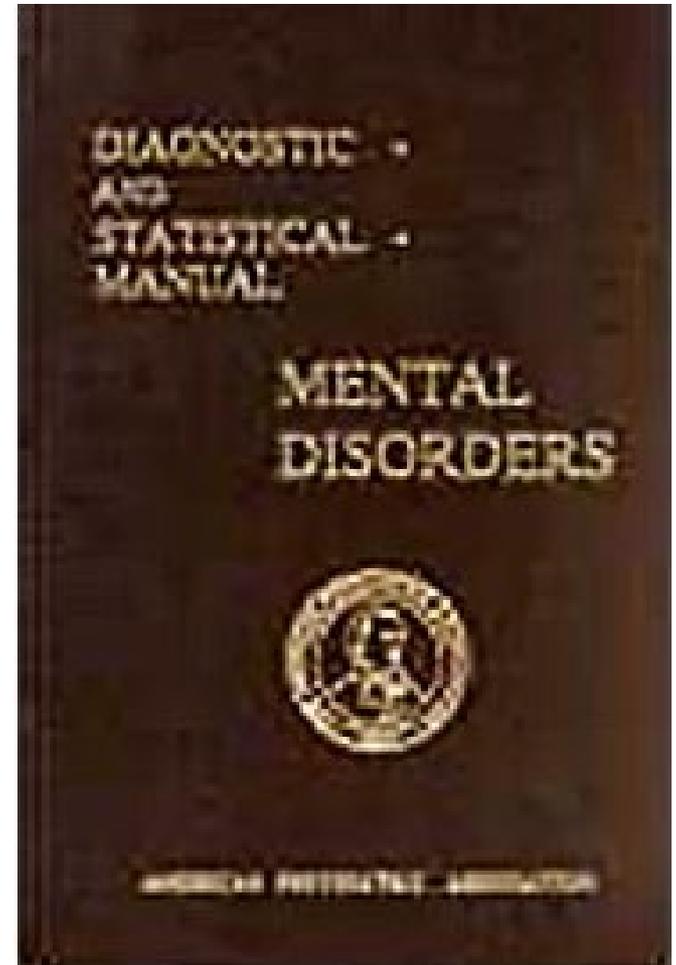




1952

- ⑥ Focus on biological lesions
- ⑥ Early life conflicts
- ⑥ Reactions due to personality, psychological, social, environmental and biological factors

Schizophrenia Reaction



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🌀 Schizophrenia was a collection of psychotic and neurotic symptoms thought to afflict women who struggled with their role of domesticity

for prompt and sustained relief from
severe mental and
**emotional
stress**



THORAZINE* SPANSULE* capsules
chlorpromazine, S.K.F. sustained release capsules, S.K.F.

30 mg. 75 mg. 150 mg. 200 mg. 300 mg.

 Smith Kline & French Laboratories

*T.M. Reg. U.S. Pat. Off.



why is this woman tired?



She may be tired for either of two reasons:

- because she is physically overworked. If this is the case, you prescribe rest, because rest is the only cure for this kind of physical tiredness.
- because she is mentally "done in". Many of your patients—particularly housewives—are crushed under a load of dull, routine duties that leave them in a state of mental and emotional fatigue. For these patients, you may find *Dexedrine* an ideal prescription. *Dexedrine* will give them a feeling of energy and well-being, renewing their interest in life and living. *Dexedrine*† (dextro-amphetamine sulfate, S.K.F.) is available as tablets, elixir, and *Spanules** capsules (sustained release capsules, S.K.F.) and is manufactured by Smith, Kline & French Laboratories, Philadelphia.



when the patient's anxiety is complicated by depression . . .

both symptoms often respond to

THORA-DEX*

(a combination of Thorazine¹ and Dexedrine²)

Thora-Dex³ is a combination of a specific anti-anxiety agent, Thorazine¹, and a standard antidepressant, Dexedrine². The preparation is of unusual value in mental and emotional disturbances and in somatic conditions complicated by emotional stress—especially when depression occurs together with anxiety, agitation or apprehension.

The patient treated with Thora-Dex³ is generally both calm and alert . . . with normal interest, activity and capacity for work.

Smith, Kline & French Laboratories, Philadelphia

Thora-Dex³ Tablets are available in two strengths:
10 mg. Thorazine¹ 25 mg. Thorazine¹
2 mg. Dexedrine² 5 mg. Dexedrine²

Thora-Dex³ should be administered discriminately and, before prescribing, the physician should be fully conversant with the available literature.

*Trademark. ¹T.M. Reg. U.S. Pat. Off. for chlorpromazine, S.K.F.
²T.M. Reg. U.S. Pat. Off. for dextro-amphetamine sulfate, S.K.F.

RAISE THE EMOTIONAL THRESHOLD

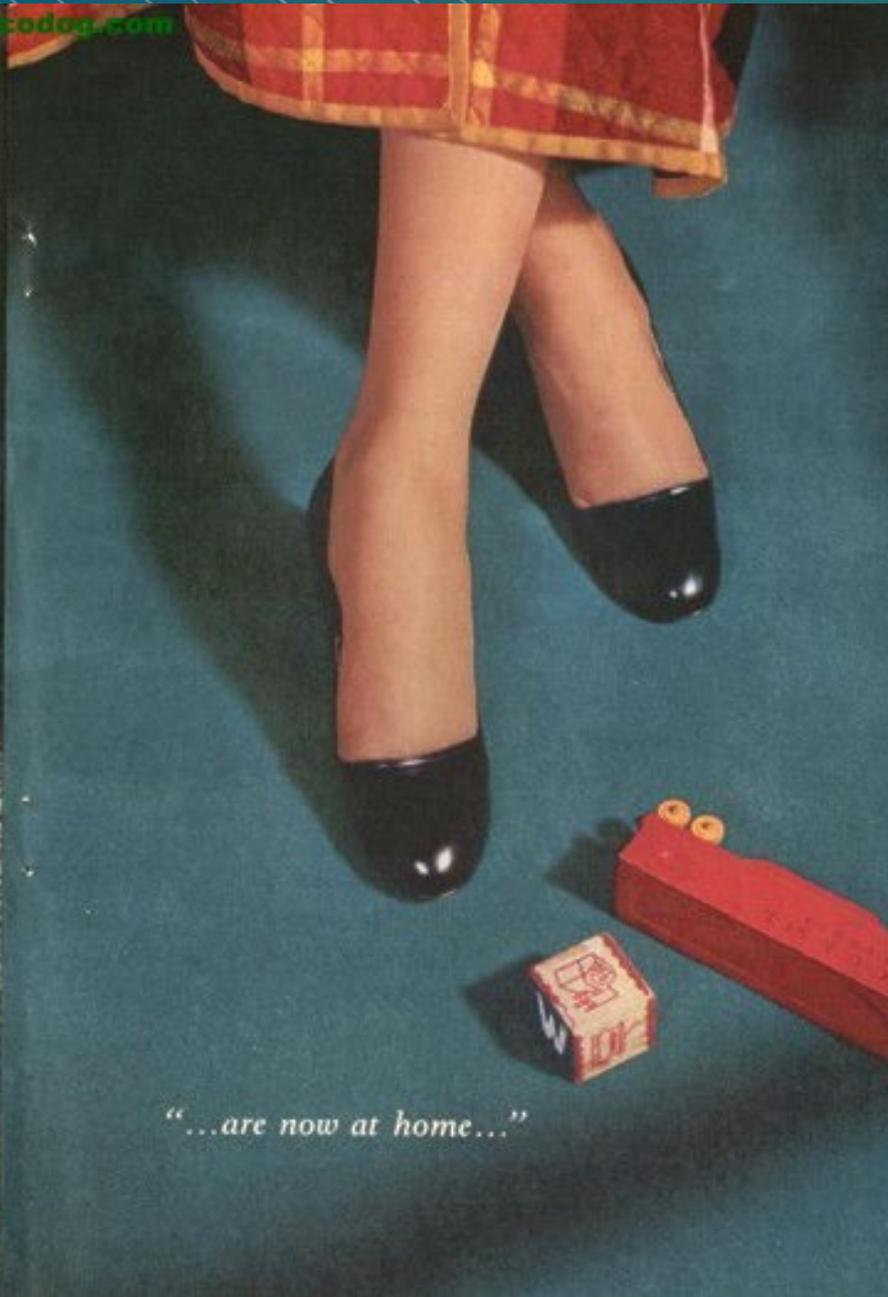
against
everyday stresses . . .

Serpasil in a LOW, ONCE-A-DAY¹ dose acts as a gentle mood-leveling agent . . . sets up a needed "tranquility barrier" for the many patients who, without some help, are incapable of dealing calmly with a daily pile-up of stressful situations.

Thioridazine (Serpasil) has been shown to have a tranquilizing effect on patients who are being treated for 1950-1951-1952-1953-1954-1955-1956-1957-1958-1959-1960-1961-1962-1963-1964-1965-1966-1967-1968-1969-1970-1971-1972-1973-1974-1975-1976-1977-1978-1979-1980-1981-1982-1983-1984-1985-1986-1987-1988-1989-1990-1991-1992-1993-1994-1995-1996-1997-1998-1999-2000-2001-2002-2003-2004-2005-2006-2007-2008-2009-2010-2011-2012-2013-2014-2015-2016-2017-2018-2019-2020-2021-2022-2023-2024-2025-2026-2027-2028-2029-2030-2031-2032-2033-2034-2035-2036-2037-2038-2039-2040-2041-2042-2043-2044-2045-2046-2047-2048-2049-2050-2051-2052-2053-2054-2055-2056-2057-2058-2059-2060-2061-2062-2063-2064-2065-2066-2067-2068-2069-2070-2071-2072-2073-2074-2075-2076-2077-2078-2079-2080-2081-2082-2083-2084-2085-2086-2087-2088-2089-2090-2091-2092-2093-2094-2095-2096-2097-2098-2099-2100-2101-2102-2103-2104-2105-2106-2107-2108-2109-2110-2111-2112-2113-2114-2115-2116-2117-2118-2119-2120-2121-2122-2123-2124-2125-2126-2127-2128-2129-2130-2131-2132-2133-2134-2135-2136-2137-2138-2139-2140-2141-2142-2143-2144-2145-2146-2147-2148-2149-2150-2151-2152-2153-2154-2155-2156-2157-2158-2159-2160-2161-2162-2163-2164-2165-2166-2167-2168-2169-2170-2171-2172-2173-2174-2175-2176-2177-2178-2179-2180-2181-2182-2183-2184-2185-2186-2187-2188-2189-2190-2191-2192-2193-2194-2195-2196-2197-2198-2199-2200-2201-2202-2203-2204-2205-2206-2207-2208-2209-2210-2211-2212-2213-2214-2215-2216-2217-2218-2219-2220-2221-2222-2223-2224-2225-2226-2227-2228-2229-2230-2231-2232-2233-2234-2235-2236-2237-2238-2239-2240-2241-2242-2243-2244-2245-2246-2247-2248-2249-2250-2251-2252-2253-2254-2255-2256-2257-2258-2259-2260-2261-2262-2263-2264-2265-2266-2267-2268-2269-2270-2271-2272-2273-2274-2275-2276-2277-2278-2279-2280-2281-2282-2283-2284-2285-2286-2287-2288-2289-2290-2291-2292-2293-2294-2295-2296-2297-2298-2299-2300-2301-2302-2303-2304-2305-2306-2307-2308-2309-2310-2311-2312-2313-2314-2315-2316-2317-2318-2319-2320-2321-2322-2323-2324-2325-2326-2327-2328-2329-2330-2331-2332-2333-2334-2335-2336-2337-2338-2339-2340-2341-2342-2343-2344-2345-2346-2347-2348-2349-2350-2351-2352-2353-2354-2355-2356-2357-2358-2359-2360-2361-2362-2363-2364-2365-2366-2367-2368-2369-2370-2371-2372-2373-2374-2375-2376-2377-2378-2379-2380-2381-2382-2383-2384-2385-2386-2387-2388-2389-2390-2391-2392-2393-2394-2395-2396-2397-2398-2399-2400-2401-2402-2403-2404-2405-2406-2407-2408-2409-2410-2411-2412-2413-2414-2415-2416-2417-2418-2419-2420-2421-2422-2423-2424-2425-2426-2427-2428-2429-2430-2431-2432-2433-2434-2435-2436-2437-2438-2439-2440-2441-2442-2443-2444-2445-2446-2447-2448-2449-2450-2451-2452-2453-2454-2455-2456-2457-2458-2459-2460-2461-2462-2463-2464-2465-2466-2467-2468-2469-2470-2471-2472-2473-2474-2475-2476-2477-2478-2479-2480-2481-2482-2483-2484-2485-2486-2487-2488-2489-2490-2491-2492-2493-2494-2495-2496-2497-2498-2499-2500-2501-2502-2503-2504-2505-2506-2507-2508-2509-2510-2511-2512-2513-2514-2515-2516-2517-2518-2519-2520-2521-2522-2523-2524-2525-2526-2527-2528-2529-2530-2531-2532-2533-2534-2535-2536-2537-2538-2539-2540-2541-2542-2543-2544-2545-2546-2547-2548-2549-2550-2551-2552-2553-2554-2555-2556-2557-2558-2559-2560-2561-2562-2563-2564-2565-2566-2567-2568-2569-2570-2571-2572-2573-2574-2575-2576-2577-2578-2579-2580-2581-2582-2583-2584-2585-2586-2587-2588-2589-2590-2591-2592-2593-2594-2595-2596-2597-2598-2599-2600-2601-2602-2603-2604-2605-2606-2607-2608-2609-2610-2611-2612-2613-2614-2615-2616-2617-2618-2619-2620-2621-2622-2623-2624-2625-2626-2627-2628-2629-2630-2631-2632-2633-2634-2635-2636-2637-2638-2639-2640-2641-2642-2643-2644-2645-2646-2647-2648-2649-2650-2651-2652-2653-2654-2655-2656-2657-2658-2659-2660-2661-2662-2663-2664-2665-2666-2667-2668-2669-2670-2671-2672-2673-2674-2675-2676-2677-2678-2679-2680-2681-2682-2683-2684-2685-2686-2687-2688-2689-2690-2691-2692-2693-2694-2695-2696-2697-2698-2699-2700-2701-2702-2703-2704-2705-2706-2707-2708-2709-2710-2711-2712-2713-2714-2715-2716-2717-2718-2719-2720-2721-2722-2723-2724-2725-2726-2727-2728-2729-2730-2731-2732-2733-2734-2735-2736-2737-2738-2739-2740-2741-2742-2743-2744-2745-2746-2747-2748-2749-2750-2751-2752-2753-2754-2755-2756-2757-2758-2759-2760-2761-2762-2763-2764-2765-2766-2767-2768-2769-2770-2771-2772-2773-2774-2775-2776-2777-2778-2779-2780-2781-2782-2783-2784-2785-2786-2787-2788-2789-2790-2791-2792-2793-2794-2795-2796-2797-2798-2799-2800-2801-2802-2803-2804-2805-2806-2807-2808-2809-2810-2811-2812-2813-2814-2815-2816-2817-2818-2819-2820-2821-2822-2823-2824-2825-2826-2827-2828-2829-2830-2831-2832-2833-2834-2835-2836-2837-2838-2839-2840-2841-2842-2843-2844-2845-2846-2847-2848-2849-2850-2851-2852-2853-2854-2855-2856-2857-2858-2859-2860-2861-2862-2863-2864-2865-2866-2867-2868-2869-2870-2871-2872-2873-2874-2875-2876-2877-2878-2879-2880-2881-2882-2883-2884-2885-2886-2887-2888-2889-2890-2891-2892-2893-2894-2895-2896-2897-2898-2899-2900-2901-2902-2903-2904-2905-2906-2907-2908-2909-2910-2911-2912-2913-2914-2915-2916-2917-2918-2919-2920-2921-2922-2923-2924-2925-2926-2927-2928-2929-2930-2931-2932-2933-2934-2935-2936-2937-2938-2939-2940-2941-2942-2943-2944-2945-2946-2947-2948-2949-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...patients hospitalized for many years...



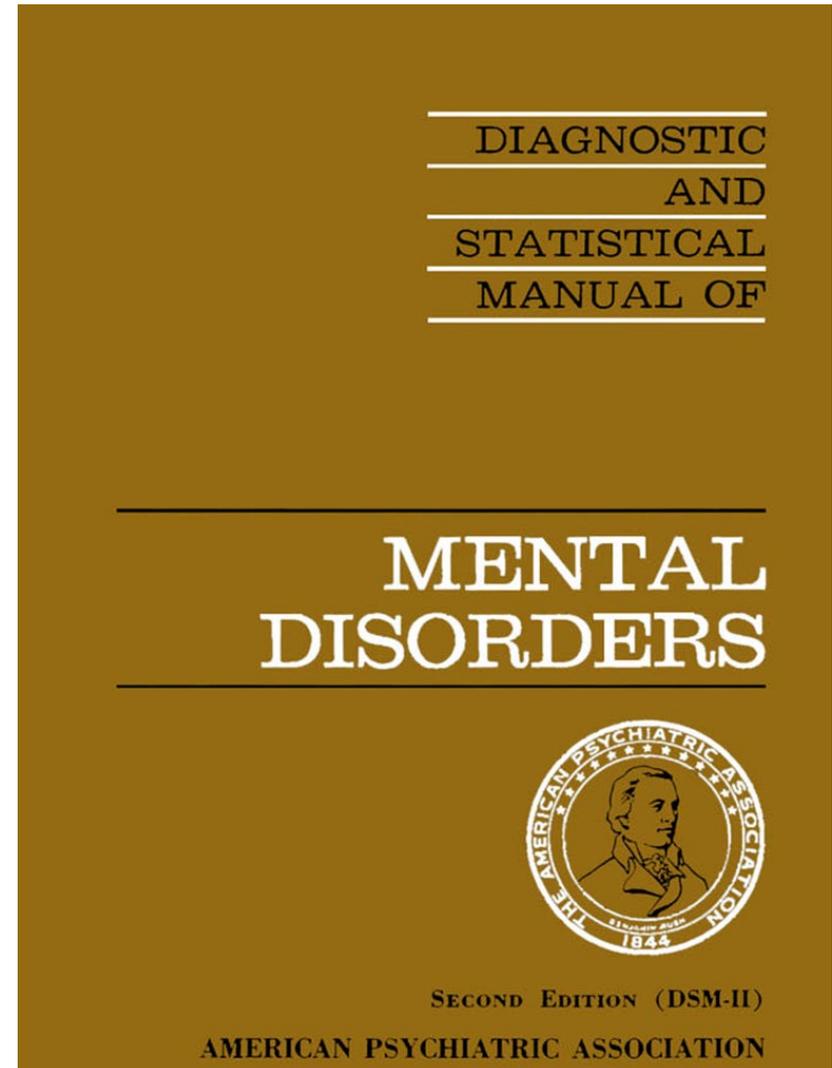
“...are now at home...”



1968

- "facilitate maximum communication within the profession and reduce confusion and ambiguity"
- Less culturally specific to the U.S.; more in line with W.H.O.'s. ICD
- Removes "Reaction"

Schizophrenia, Paranoid Type



Our Movement. Our Moment.

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“Many people are so uncomfortable with the stigma associated with mental illness that they would rather suffer in silence than get the help they need” Pat Deegan

It's pronounced...
[skit-suh-FREE-nee-uh]
not
[KREY-zee]

Our Movement. Our Moment.

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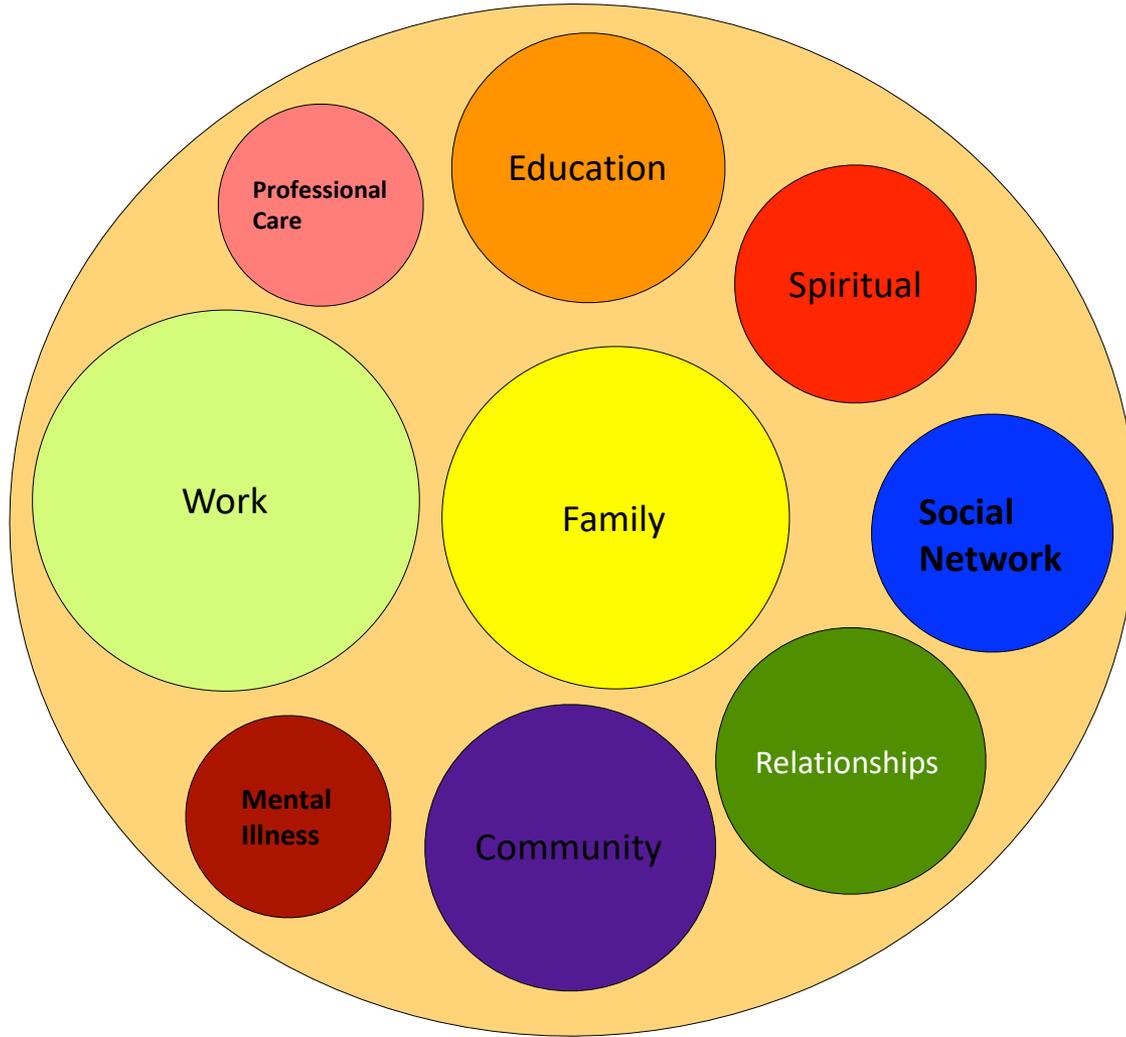
“The mystery of human existence lies not in just staying alive, but in finding something to live for. “

- Fyodor
Dostoyevsky



BUT, WHAT IF WE FLIP THE SCRIPT?...





**NOTHING IS IMPOSSIBLE.
THE WORD ITSELF SAYS
I'M POSSIBLE**

—AUDREY HEPBURN

Our Movement. Our Moment.

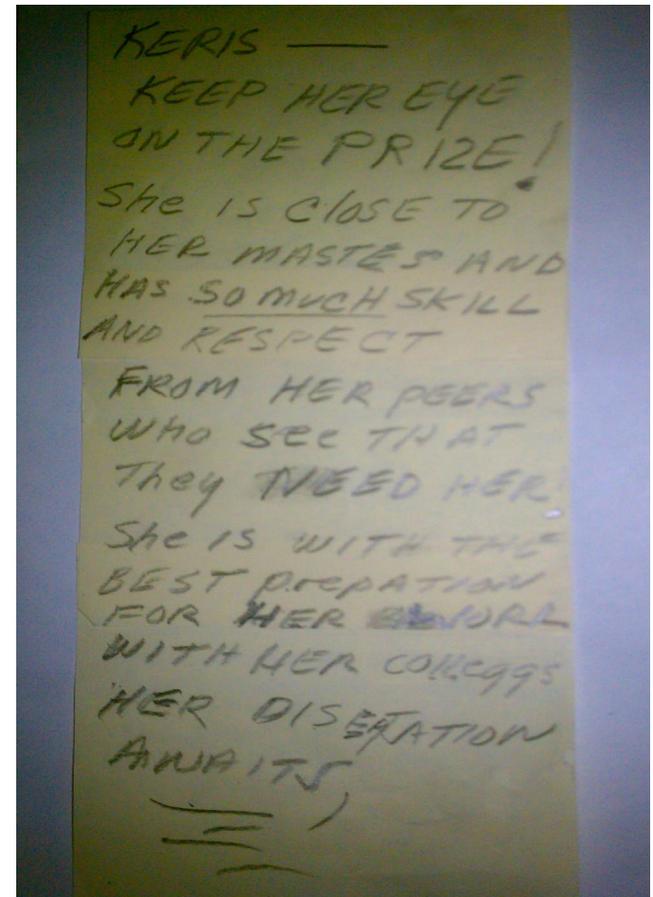
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The Power of Resilience and Recovery





Our Movement. Our **Moment.**

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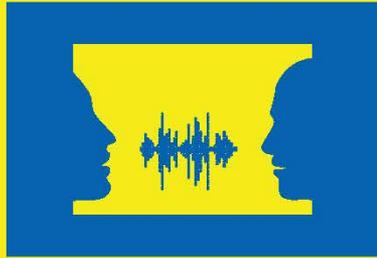
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The Power of Peer Support



DOES PEER SUPPORT MAKE A DIFFERENCE?



HOW DOES PEER SUPPORT HELP?

The role of a peer support worker complements, but does not duplicate or replace the roles of therapists, case managers, and other members of a treatment team. Consider someone who received a prosthetic arm after an accident. Clinical staff would explain how the new arm works, how to take it off and put it on, and how to care for it. A peer supporter who shares the experience of losing a limb, however, would be able to empathize with the person about what it is like to receive a prosthetic arm, the experience of introducing it to one's family, and how it feels to go out in public with it.

Peer support workers bring their own personal knowledge of what it is like to live and thrive with mental health conditions and substance use disorders. They support people's progress towards recovery and self-determined lives by sharing vital experiential information and real examples of the power of recovery. The sense of mutuality created through thoughtful sharing of experience is influential in modeling recovery and offering hope (Davidson, Bellamy, Guy, & Miller, 2012).

Emerging research shows that peer support is effective for supporting recovery from behavioral health conditions. Benefits of peer support may include



Increased self-esteem and confidence (Davidson, et al., 1999; Salzer, 2002);



Increased sense of control and ability to bring about changes in their lives (Davidson, et al., 2012);



Raised empowerment scores (Davidson, et al., 1999; Dumont & Jones, 2002; Ochocka, Nelson, Janzen, & Trainor, 2006; Resnick & Rosenheck, 2008);



Increased sense that treatment is responsive and inclusive of needs (Davidson, et al., 2012);



Increased sense of hope and inspiration (Davidson, et al., 2006; Ratzlaff, McDiarmid, Marty, & Rapp, 2006);



Increased empathy and acceptance (camaraderie) (Coatsworth-Puspokey, Forchuk, & Ward-Griffin, 2006; Davidson, et al., 1999);



Decreased psychotic symptoms (Davidson, et al., 2012); and



Increased engagement in self-care and wellness (Davidson, et al., 2012);



Reduced hospital admission rates and longer community tenure (Chinman, Weingarten, Stayner, & Davidson, 2001; Davidson, et al., 2012; Forchuk, Martin, Chan, & Jenson, 2005; Min, Whitecraft, Rothbard, Salzer, 2007);



Increased social support and social functioning (Kurtz, 1990; Nelson, Ochocka, Janzen, & Trainor, 2006; Ochocka et al., 2006; Trainor, Shepherd, Boydell, Leff, & Crawford, 1997; Yanos, Primavera, & Knight, 2001);



Decreased substance use and depression (Davidson, et al., 2012).

Our Movement. Our Moment.

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Office of the Discipline Chiefs



Jorge Partida del Toro, PhD
Chief, Psychology

Yvette Willock, LCSW, MA
Chief, Social Services

David Ruskin, MD
Chief, Psychiatry

Keris Jän Myrick MBA, MS,
Chief Peer Services

Lu Ann Sanderson, DNP
Chief, Nursing

Office of the Discipline Chiefs

Jorge Partida del Toro, PhD
Chief, Psychology

Yvette Willock, LCSW, MA
Chief, Social Services

David Ruskin, MD
Chief, Psychiatry

Keris Jän Myrick MBA, MS,
Chief Peer Services

Lu Ann Sanderson, DNP
Chief, Nursing





Mom?
What is...Normal?

It's just a setting
on the dryer, honey.

Improved Treatments

Improved Service Systems

Positive Quality of Life

Lives Saved

A silhouette of two hands holding a cutout of the word "HOPE" against a bright, cloudy sky at sunset. The sun is positioned behind the word, creating a lens flare effect. The hands are positioned on either side of the word, with fingers gripping the edges. The sky is filled with soft, white and yellow clouds, and a faint rainbow is visible in the lower-left corner.

HOPE

More Supports

More Inclusion

Greater Acceptance

A Better Understanding

WASHROOM FOR EVERYONE



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Keris Jän Myrick, MBA, MS

Chief, Peer Services
Los Angeles County Department of Mental Health

Kmyrick@dmh.lacounty.gov

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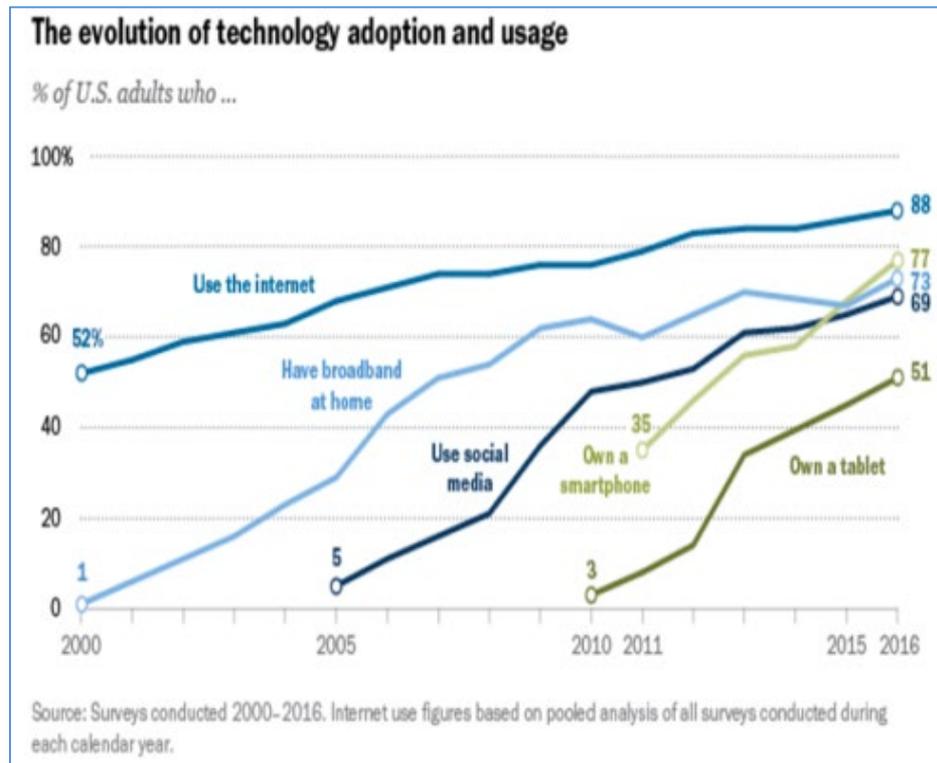


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Disparities in Digital Mental Health: Towards Closing the Gap

John Torous

What Does Increasing Access to Smartphones Mean?



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Offline population has declined substantially since 2000

% of U.S. adults who say they do not use the internet

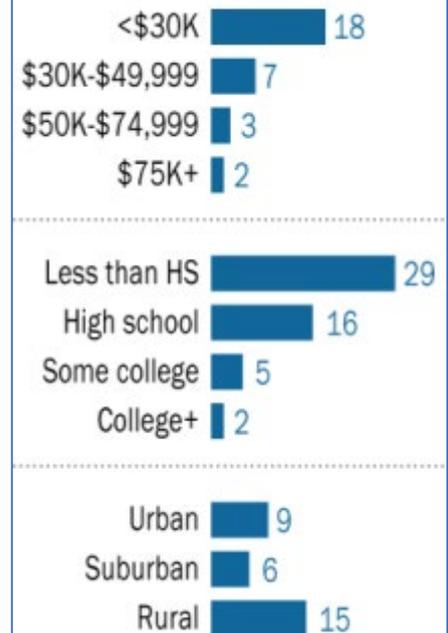
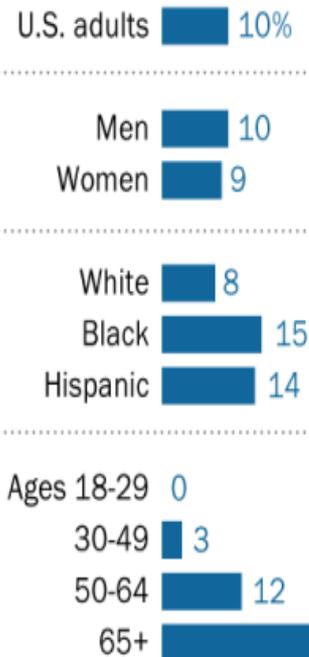


Source: Survey conducted Jan. 8-Feb. 7, 2019. Trend data from previous Pew Research Center surveys.

PEW RESEARCH CENTER

Who's not online in 2019?

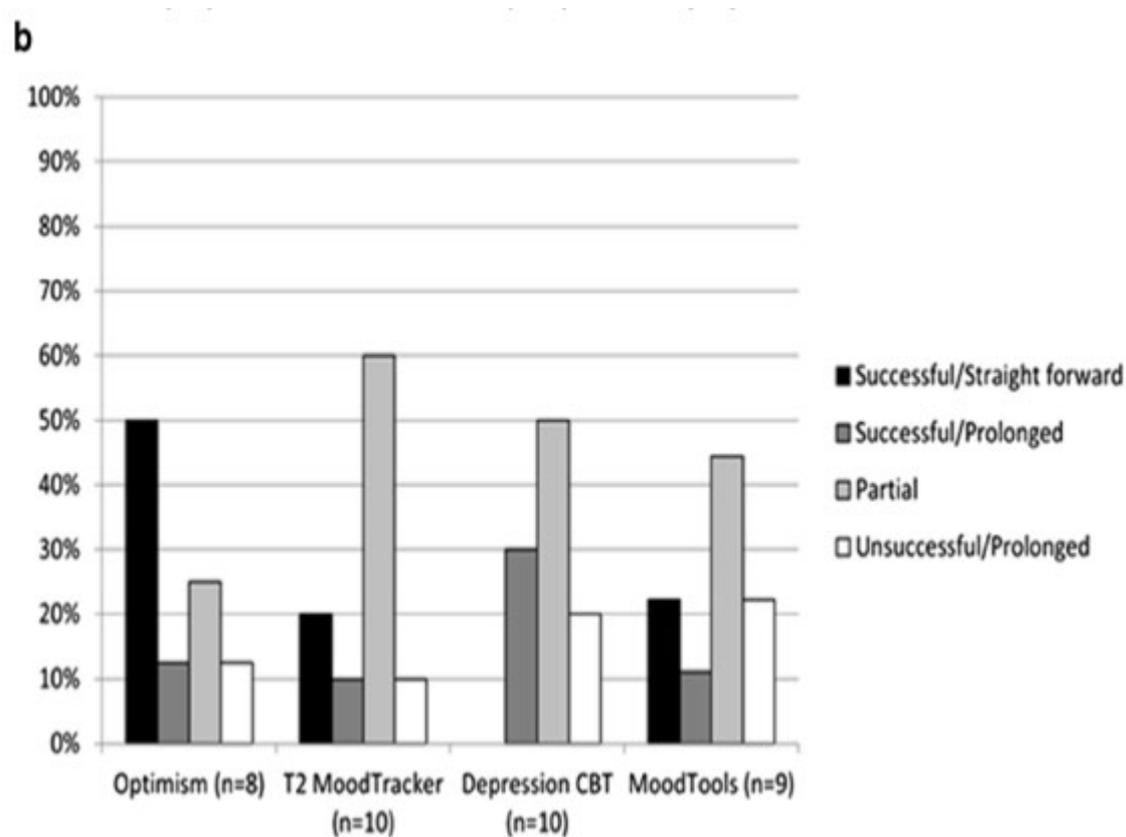
% of U.S. adults who say they do not use the internet



Note: Whites and blacks include only non-Hispanics. Hispanics are of any race.
Source: Survey conducted Jan. 8-Feb. 7, 2019.

PEW RESEARCH CENTER

Most Apps are Not Easy To Use



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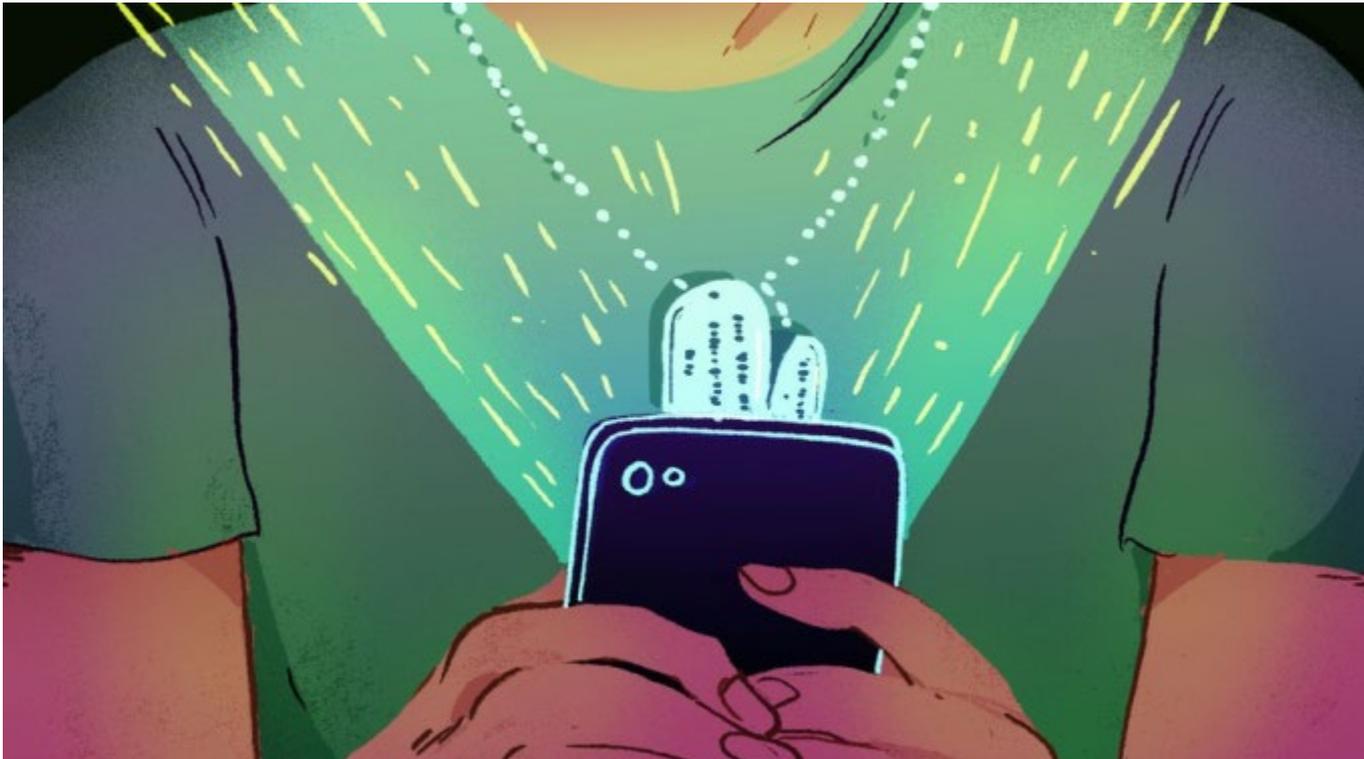
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“They told me I am too sick to use it...”



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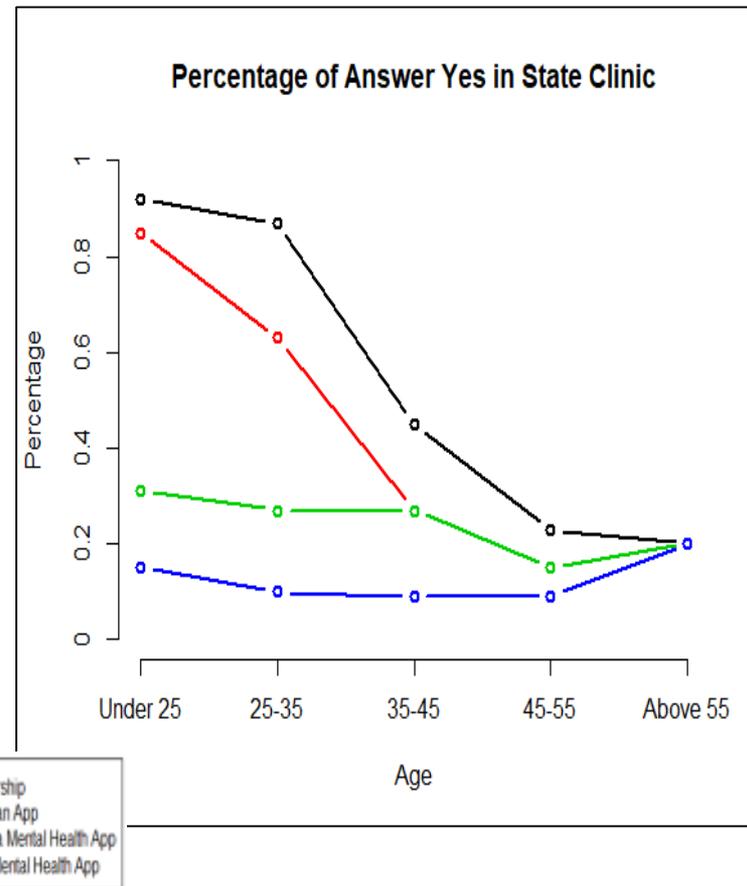
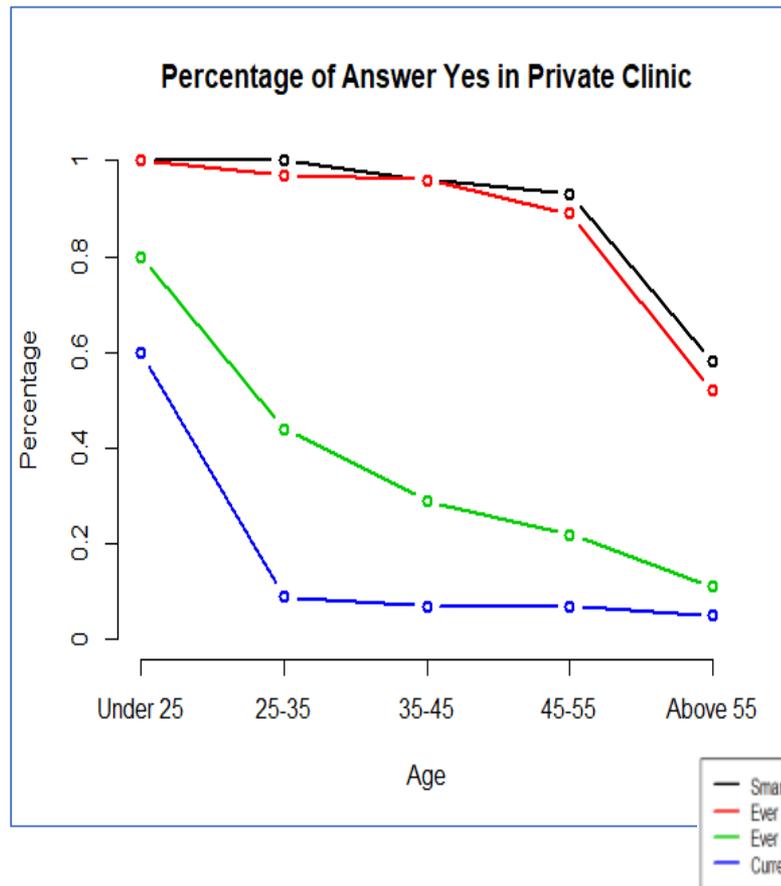
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A Second Digital Divide





Is it a Medical Device

“First, what an app claims to do matters. Many apps that target symptoms without claiming to diagnose, treat, or mitigate disease are exempt from FDA oversight.”

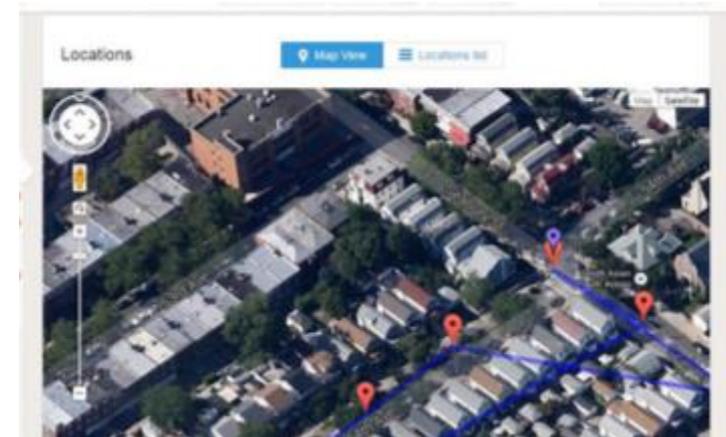
“A second theme is that the potential for harm to a user matters. The FDA has indicated that apps that pose a high potential for harm are subject to review.”

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Diagnosis by Smartphone



J. Torous, "Digital psychiatry," in *IEEE Spectrum*, vol. 54, no. 7, pp. 45-50, July 2017.

What Do Apps Offer Users?



	Anxiety (n=40)	Schizophrenia (n=40)	Depression (n=40)	Diabetes (n=40)	Addiction (n=40)	Hypertension (n=40)
User Star Ratings	4.29	4.18	4.41	4.35	4.44	4.10
Presence of a Privacy Policy	85%	50%	85%	85%	70%	45%
Ability to Delete Data	70%	20%	70%	60%	45%	25%
Costs Associated with the App	70%	15%	65%	40%	65%	60%
Days Since Last Update	58	462	139	37	166	687
Medical Claims by App	15%	30%	45%	45%	5%	45%
Specific Evidence to Support Medical Claims	5%	10%	0%	5%	0%	0%

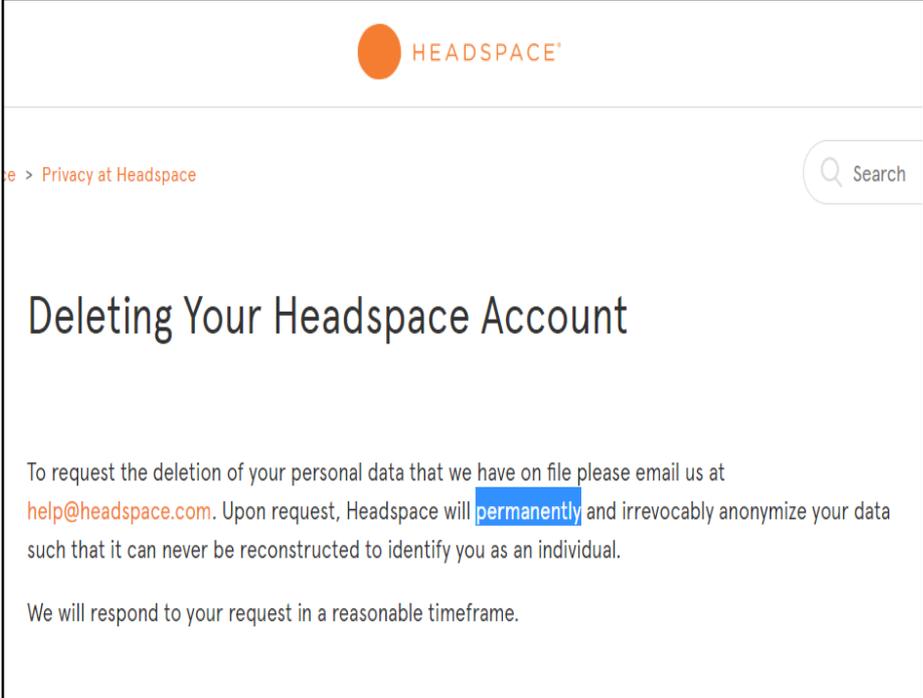
Can You Understand What It Demands?



	Reading Level of Privacy Policy
Mental Health Apps	13.6
Diabetes Apps	13.9

A Privacy Loophole

- **10. MEDICAL DISCLAIMER**
- 10.1 Headspace is a provider of online and mobile meditation content in the health & wellness space. We are **not** a health care or medical device provider, nor should our Products be considered medical advice. **Only your physician or other health care provider can do that.** While there is third party evidence from research that meditation can assist in the prevention and recovery process for a wide array of conditions as well as in improving some performance and relationship issues, **Headspace makes no claims, representations or guarantees that the Products provide a therapeutic benefit.**



HEADSPACE

e > Privacy at Headspace

Search

Deleting Your Headspace Account

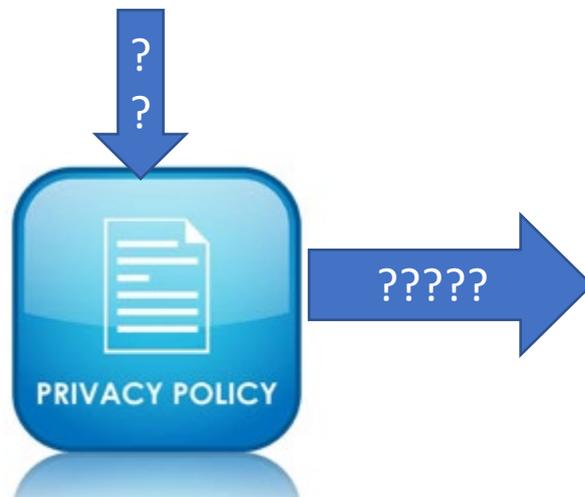
To request the deletion of your personal data that we have on file please email us at help@headspace.com. Upon request, Headspace will **permanently** and irrevocably anonymize your data such that it can never be reconstructed to identify you as an individual.

We will respond to your request in a reasonable timeframe.

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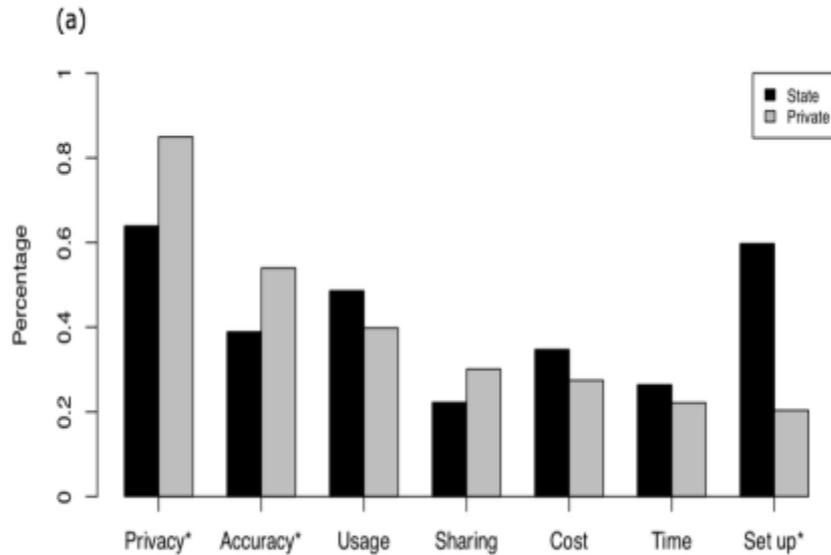
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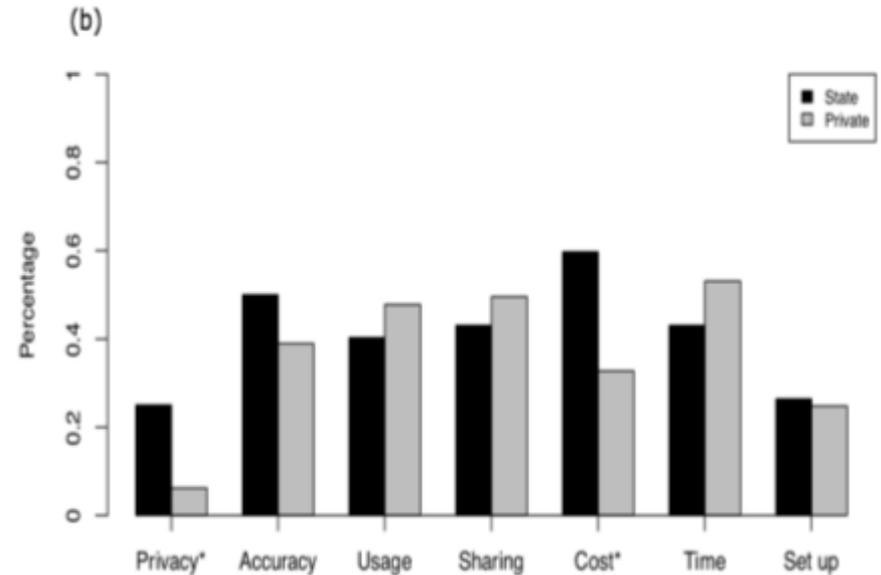


	Data transmission captured		Transmission disclosed in a policy ²	
	n	(%) ¹	n	(%) ³
Any third-party destination	33	(92%)	16	(48%)
Google destinations	28	(78%)	13	(46%)
Google advertising services ⁴	15		6	
Google analytics services ⁵	22		10	
Facebook Analytics	12	(33%)	7	(58%)
Others	20	(56%)	13	(65%)
Mixpanel	4		3	
AppNexus	3		2	
Twitter Mopub	3		3	
Yahoo Flurry Analytics	3		2	
AdColony	2		1	
AppsFlyer	2		1	
Kiip	2		1	
Branch	1		0	
AddThis	1		1	
Amplitude	1		1	
Manage.com	1		1	
Singular / Apsalar	1		1	
UserVoice	1		1	
(Unknown destination) ⁶	1	(3%)	0	(0%)

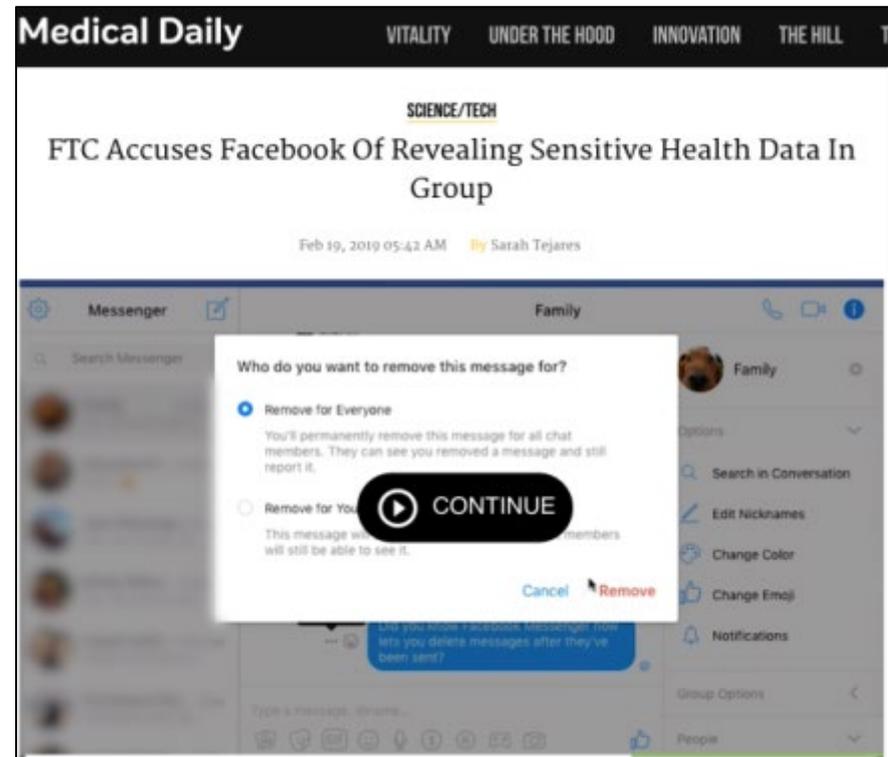
Concerns



Benefits



Lack of Informed Consent



Barnett I, Torous J. Ethics, transparency, and public health at the intersection of innovation and Facebook's suicide prevention efforts. *Annals of internal medicine*. 2019 Feb 12.

Solution = Knowledge and Skills

Modules

Session 2: Capturing Lived Experience

In this session, group members will explore the ways in which smartphone technology can be used to illustrate connections between behaviors, symptoms, and mood. Participants will consider how capturing their lived experience can help them understand their own patterns and make health-related goals based on the insights they derive from their personal data. InUY members will help group members download the LAMP app and demonstrate how to use the survey function to track various elements of participants' lived experience (e.g. mood, anxiety, psychosis, sleep, medication). During the session wrap-up, participants will discuss what aspect of their lived experience they would like to monitor over the next week and what they hope to learn from using this digital tool.

Time: 1 hour

Session outline:

1. Review group purpose
2. Check on Sleep, Behavior, & Think
3. Connections between behaviors, symptoms, and mood
4. Monitoring behaviors, symptoms, and mood
5. Using smartphone apps (LAMP) to capture lived experience
6. Action planning and wrap-up

Facilitator pre-session preparation:

- Confirm Wi-Fi access or bring hotspot device (if Wi-Fi is limited in the building)
- Confirm access to laptop screen to share survey results (e.g. TV screen, projector, monitor)
- Confirm ability to connect staff smartphone to monitor for LAMP demo
- Download LAMP onto multiple iPads for use during group session (optional)
- Practice using LAMP prior to group session to increase confidence in assisting participants in navigating through the app
- Create LAMP study ID's for group participants
- Create digital goal and prize link/instructions for participants (www.directpoll.com)

Materials needed: 5-7 iPads, Large screen and/or projector

1) Review group purpose

"Hello everyone. Before we get started, I wanted to provide a quick review of what we're doing in this group for those of you who may not have been here last week. The purpose of this group is to learn about how you can use your smartphone to better understand your own experiences and to find out how things like sleep, exercise, and exercising might be connected to your mood and how you feel overall. We'll work together to identify some good apps that fit your needs and how these apps might support you in reaching your health goals.

Before I go any further, does anyone have any questions or concerns from our last group meeting?"

LAMP Screenshots



Now we'll split into small groups and help each one of you to download the app."

- Provide each patient with a study ID and assist them with the download process (see Appendix B)
- Record participant names and study ID

Tip: If participants are not able/interested in downloading the LAMP app, staff can assist them with locating the app store feature on their smartphones. This feature is located within the *HealthKit* applications for iPhones and within the *Google Fit* application for Android.

4) Action planning and wrap-up

"Now that all of you have downloaded the app, we want to think about what you're most interested in keeping track of throughout the week. Through LAMP you can track sleep, step count, psychosis symptoms, anxiety, and depression."

Discussion prompts:

- What surveys are you thinking of using?
- What do you want to learn about yourself?
- How might this info be helpful for you?

"Next week, we're going to bring in graphs that will show you how you've been doing each day of the week!"

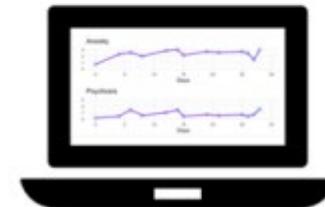
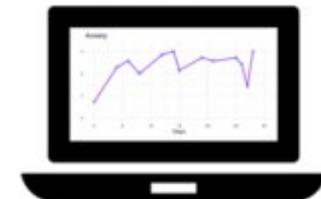
Tip: The group facilitator can show a graph directly from LAMP or create another data visualization that captures the weekly results from one survey (e.g. sleep, psychosis, anxiety, etc.)

"The more surveys you do the better your graph will be, so please try to take some every day if you can. Any other questions or comments as we wrap up?"

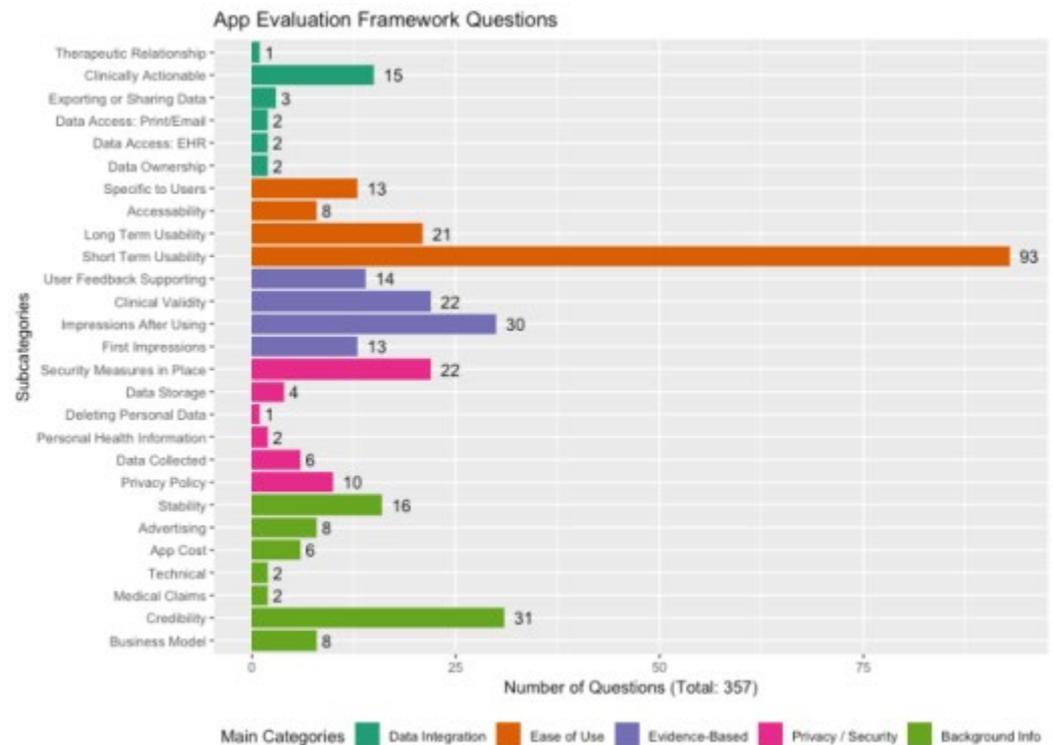
Appendix C

Session 3: Understanding lived experience and enhancing self-management strategies

Data Visualizations



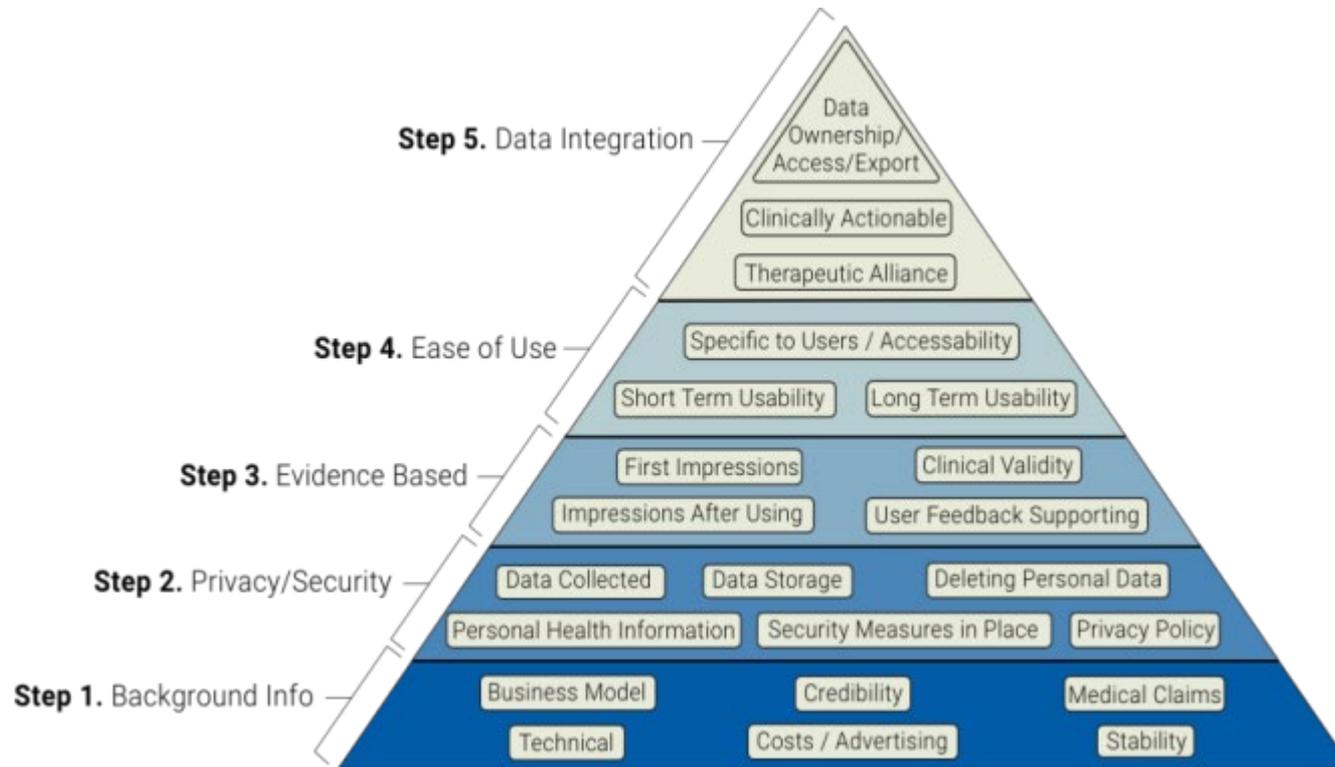
False Starts



Powell AC, Torous J, Chan S, Raynor GS, Shwartz E, Shanahan M, Landman AB. Interrater reliability of mHealth app rating measures: analysis of top depression and smoking cessation apps. JMIR mHealth and uHealth. 2016;4(1):e15.

Philip Henson, Gary David, Karen Albright, John Torous. Deriving a practical framework for the evaluation of health apps. The Lancet Digital Health. Volume 1, Issue 2, 2019.

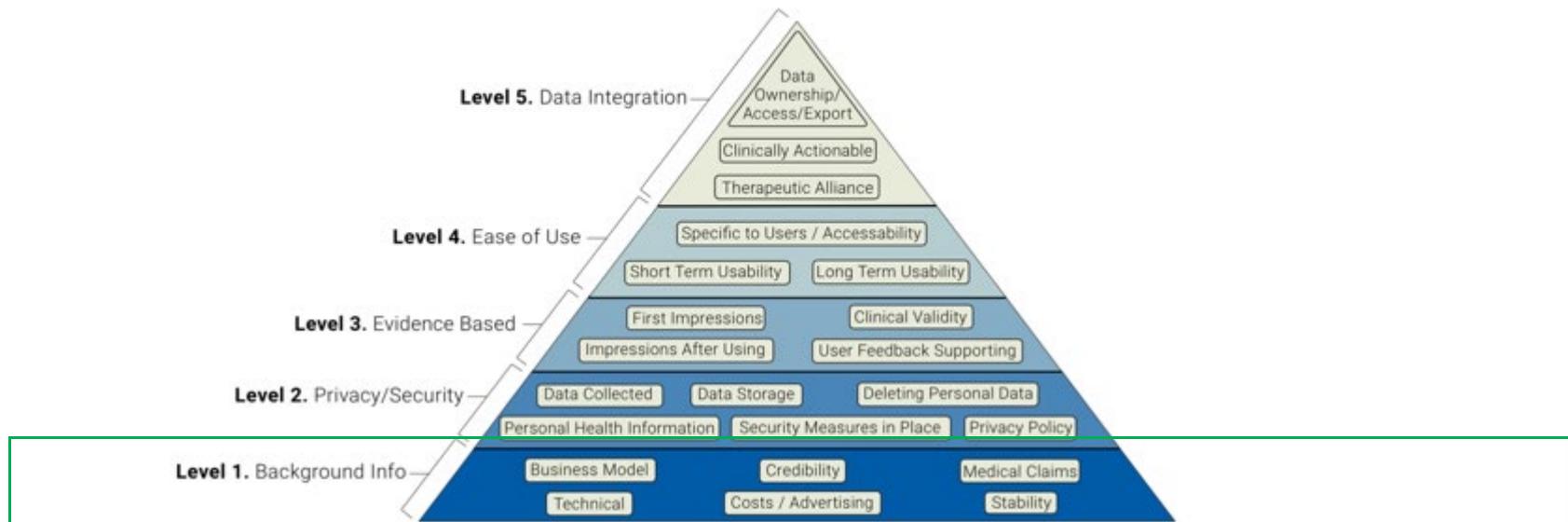
Solution = Knowledge and Skills



Solution = Knowledge and Skills



Step 1



- | | | |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Level 1: Background Info</p> <ul style="list-style-type: none"> • Does the app identify funding sources and conflicts of interest? • Does the app identify ownership? • Does the app come from a legitimate source? • Where does app info originate? • Are there additional or hidden costs? • Does the app need an active internet connection? • On what platforms does the app operate? • Has the app been updated in the last 180 days? | <p>Level 2: Privacy/Security</p> <ul style="list-style-type: none"> • Is there a privacy policy? • Does the app declare data use and purpose? • Does the app describe use of PHI? • Can you opt out of data collection or delete data? • Are data maintained on the device or the web? • Does the app explain security systems used? <p>Level 3: Evidence Based</p> <ul style="list-style-type: none"> • Does the app do what it claims to do? • Is app content correct, well-written, and relevant? • Are references included with the app? • Is there evidence of benefit from end user feedback? | <p>Level 4: Ease of Use</p> <ul style="list-style-type: none"> • Are there potential barriers to access? • Can the user easily understand how to use the app? • Is the app easy to use on a long-term basis? • Does the app clearly define its functional scope? <p>Level 5: Data Integration</p> <ul style="list-style-type: none"> • Do you own your data? • Can you easily access your data? • Can you easily share your data? • Does the app lead to any positive behavior change? • Does the app improve therapeutic alliance between patient and provider? |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

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U.S. Department of Veterans Affairs

Information

Seller	US Department of Veterans Affairs (VA)
Size	89.1 MB
Category	Health & Fitness
Compatibility	Requires iOS 9.0 or later. Compatible with iPhone, iPad, and iPod touch.
Languages	English
Age Rating	Rated 12+ for the following: Infrequent/Mild Medical/Treatment Information
Copyright	© 2011 US Department of Veterans Affairs
Price	Free

[Developer Website](#) ➤ [App Support](#) ➤ [License Agreement](#) [Privacy Policy](#) ➤

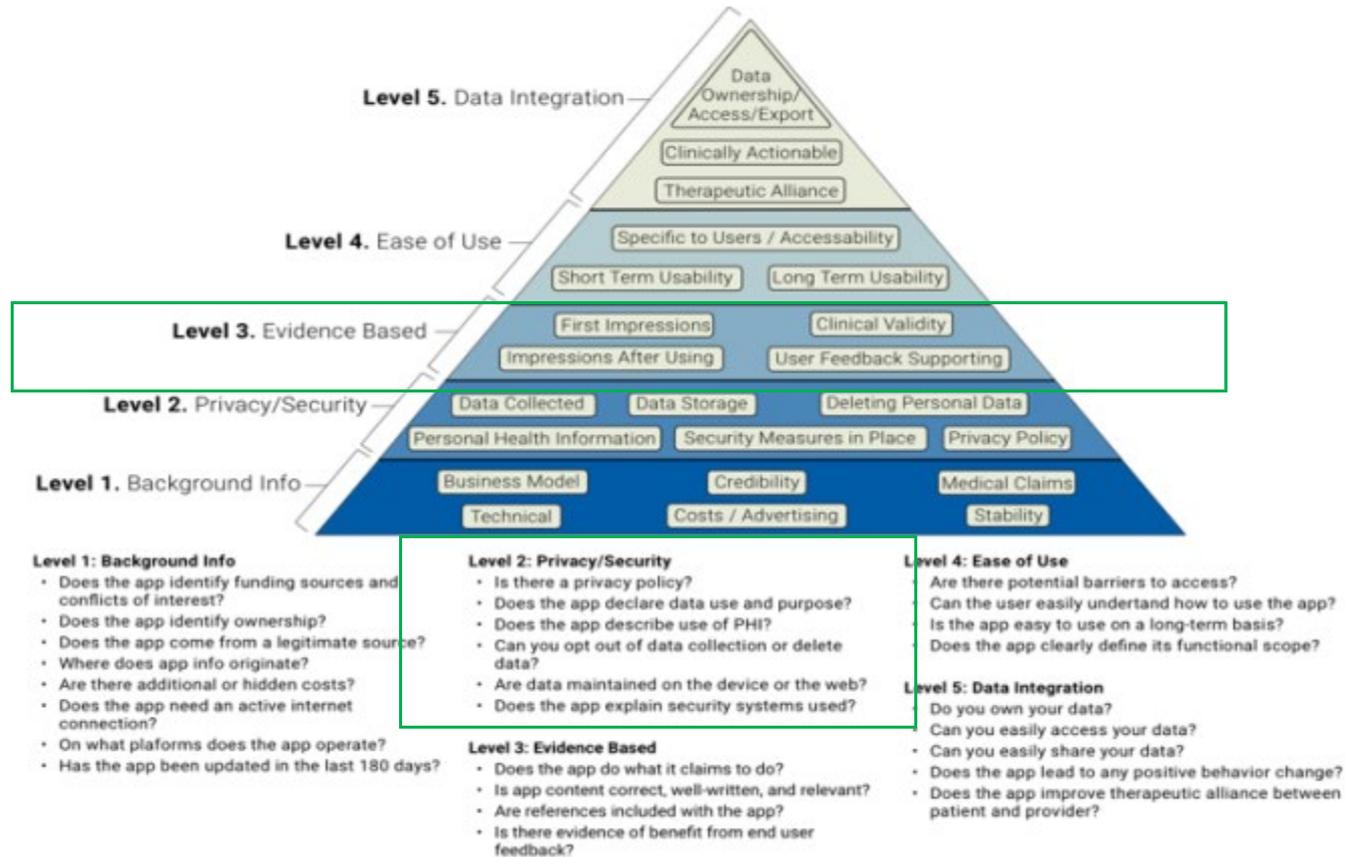
Version History

3.0	Aug 1, 2017
Improved and expanded tools for managing symptoms PCL-5 assessment Expanded educational topics User interface and graphics enhancements	
1.51	Nov 13, 2015
iOS 9 compatibility bug fixes and performance enhancements	
1.5	Nov 10, 2015
Updated for iOS 9 Bugfixes and performance enhancements	
1.0.1	Apr 13, 2011
Bug fixes and additional accessibility refinements.	
1.0	Apr 7, 2011

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Privacy Policy for Mobile Apps:

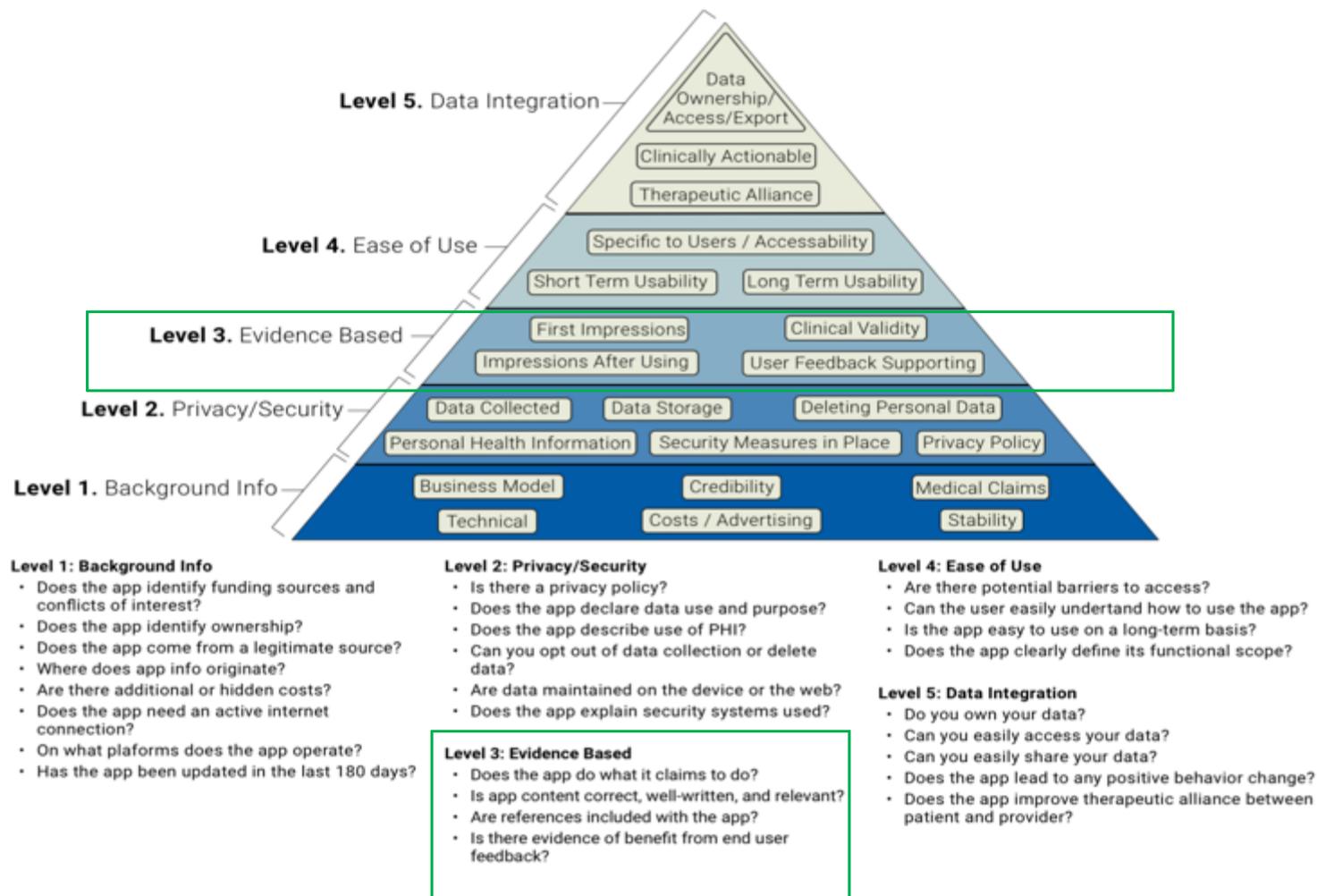
No individually identifiable data is transferred or transmitted to VA in any way through the use of the app. All individually identifiable data entered by you remains your sole property and will not be accessed by VA without your further express consent. You also acknowledge that it is your sole responsibility to protect and otherwise secure any information captured and stored by the software once installed on your device.

For statistical purposes VA collects anonymous usage data and sends it to a data provider. This feature can be disabled through the app's settings screen at any time.

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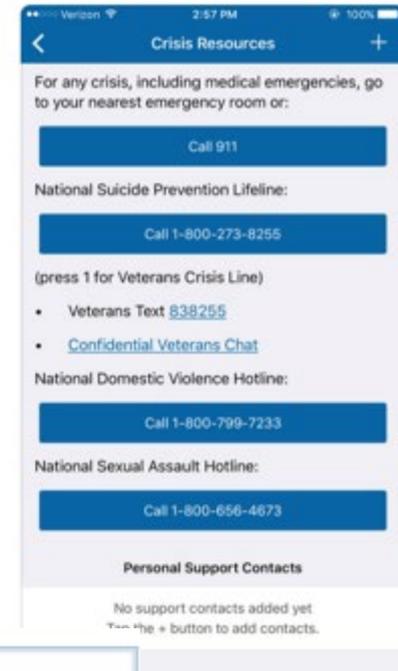
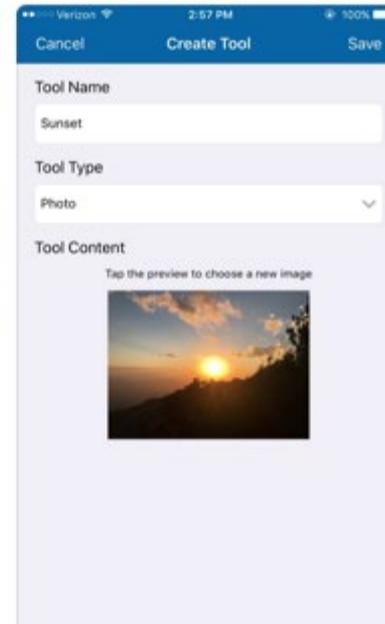
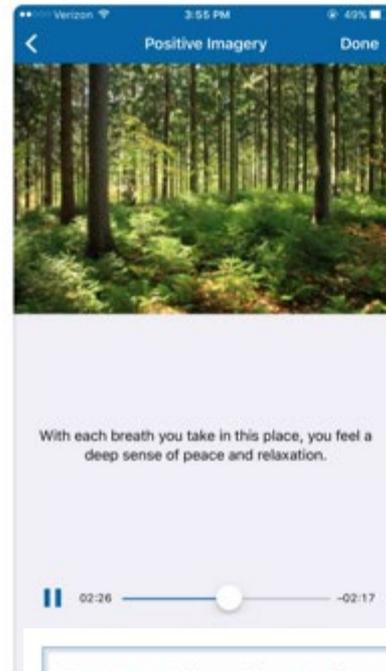


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iPhone Screenshots



Best matches for ptsd coach:

[Development and refinement of a clinician intervention to facilitate primary care patient use of the PTSD Coach app.](#)
Possemato K et al. *Transl Behav Med.* (2017)

[PTSD Coach around the world.](#)
Kuhn E et al. *Mhealth.* (2018)

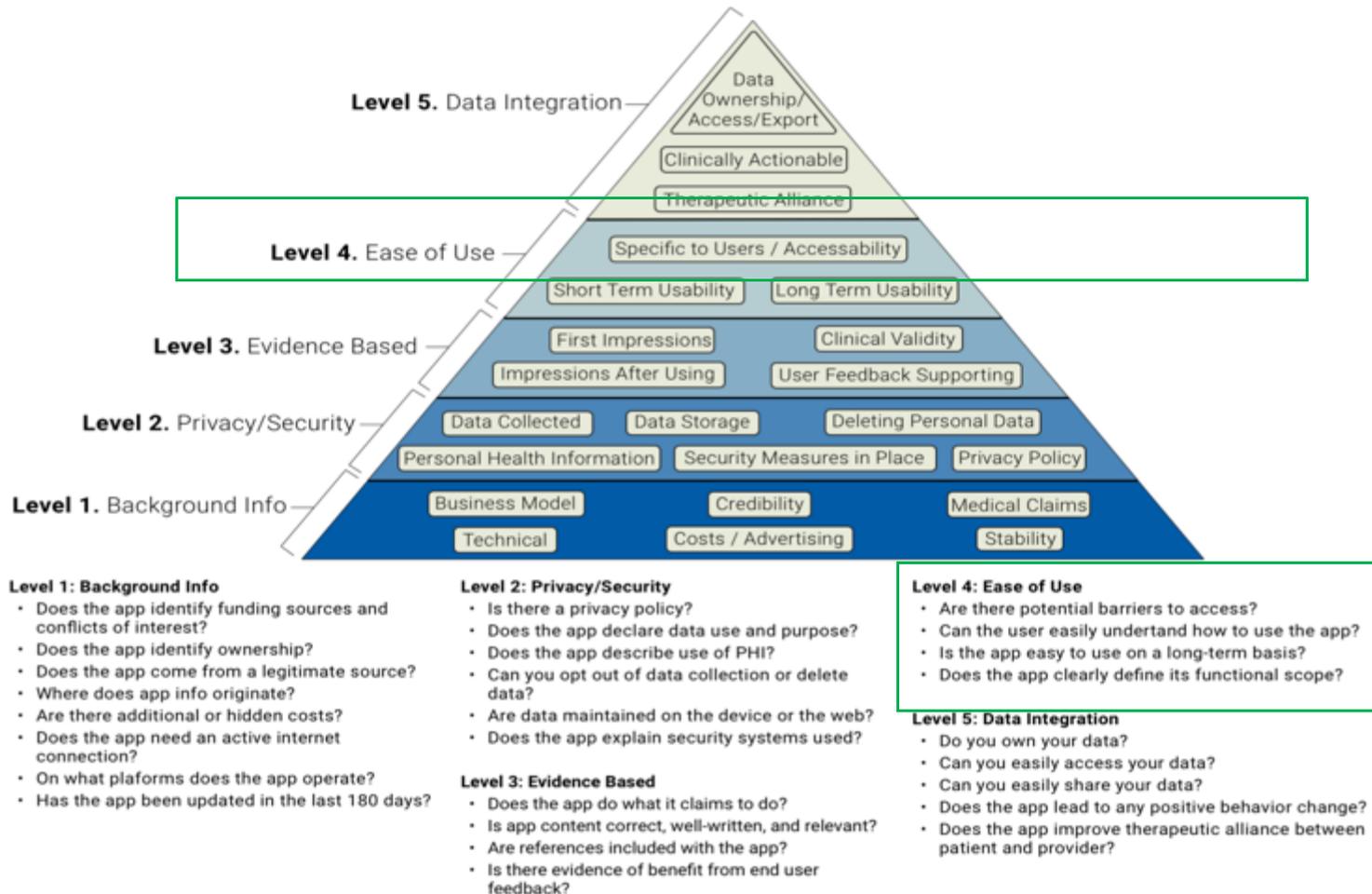
[Using PTSD Coach in primary care with and without clinician support: a pilot randomized controlled trial.](#)
Possemato K et al. *Gen Hosp Psychiatry.* (2016)

[Switch to our new best match sort order](#)

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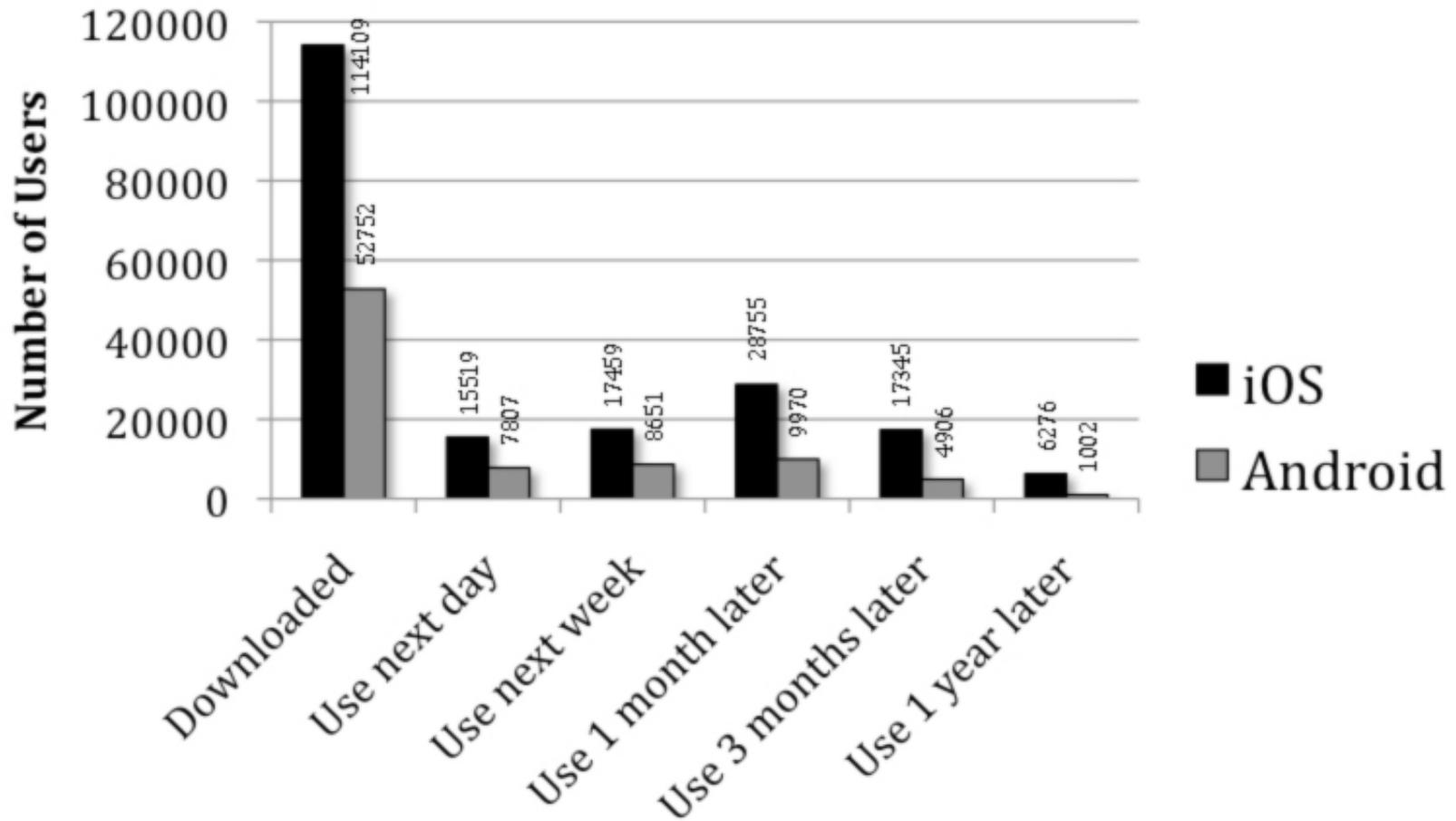
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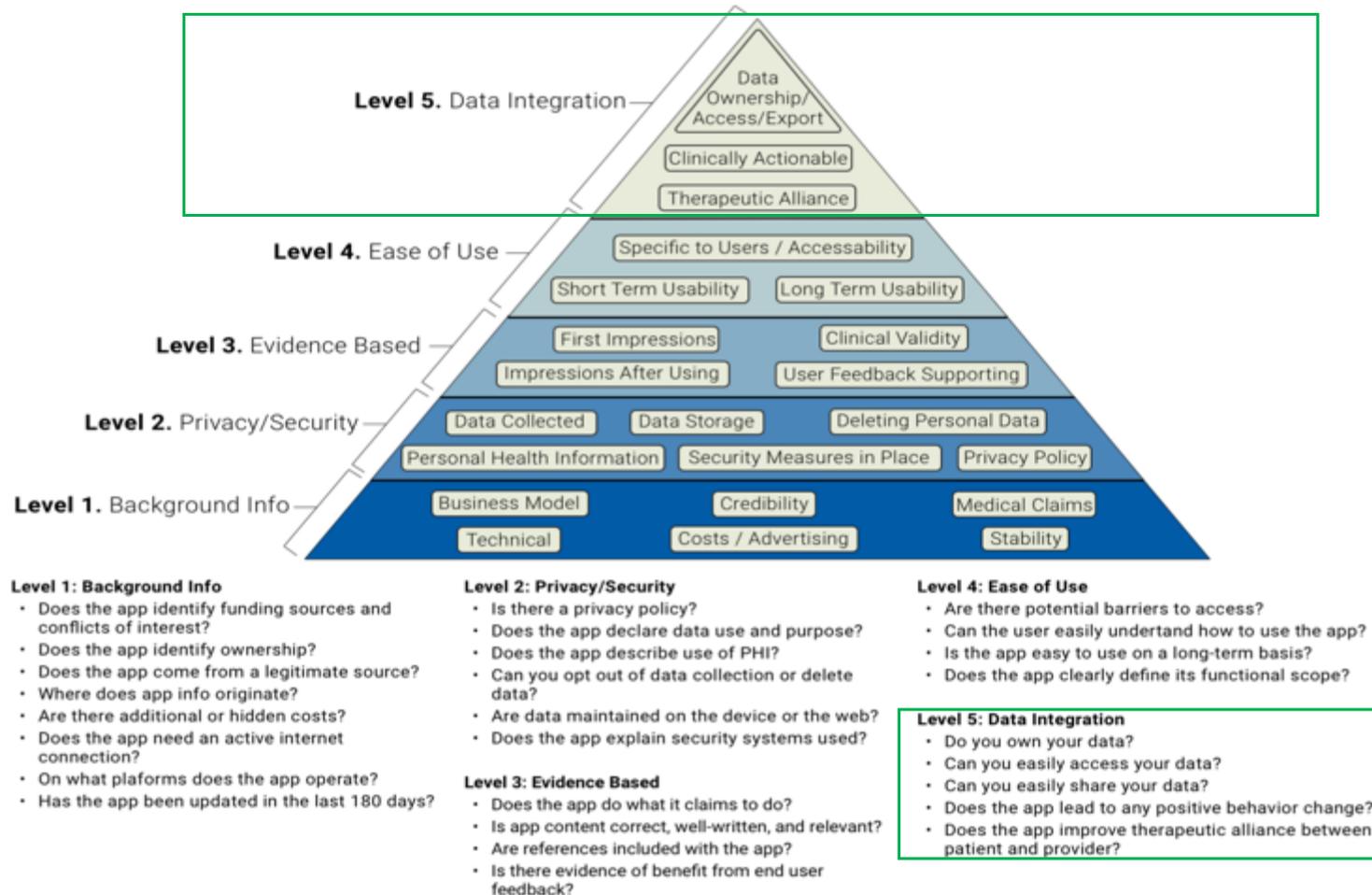
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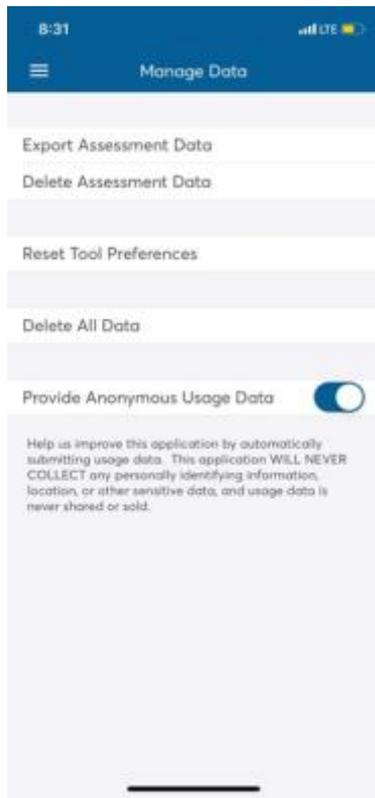
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Solution = Knowledge and Skills

The screenshot shows the SMI Adviser website interface. At the top left is the SMI Adviser logo, described as 'A Clinical Support System for Serious Mental Illness'. To the right, it says 'An APA and SAMHSA Initiative' and includes logos for 'AMERICAN PSYCHIATRY' and 'SAMHSA'. A navigation menu contains 'CLINICIANS', 'PATIENTS + FAMILIES', 'ABOUT US', 'CALENDAR', and 'CONTACT'. Below the navigation is a search bar with the text 'Search Results For: apps'. A box indicates '17 RESULT(S) FOUND'. There are pagination buttons for '1', '2', and 'NEXT'. A search input field contains the text 'apps'. On the right side, there is a 'Filter By' section with a list of categories: Events (purple), Education (blue), Knowledge Base (Clinicians) (green), Knowledge Base (Families+Patients) (orange), and Page (grey). Below that is a 'Topics' section with a list of categories: Co-morbid Medical Conditions (grey), Co-morbid Substance Use Disorders (grey), and Editor's Choice Collections (grey). The main content area displays three search results:

- What are the best apps for SMI?**
Type: Knowledge Base (Clinicians)
Answered by: John Torous, MD, MBL, SMI Technology Expert - Harvard Medical School
Topic: Technology
Tags: Apps, Self-management
- Informed Decision Making for Picking SMI Smartphone Apps**
Topics will include considerations for the privacy/safety, evidence, engagement, and interoperability of SMI apps...
Type: Education Course
Course Start Date: Feb 1, 2019
Course End Date: Feb 1, 2022
Activity Type: OnDemand
- Are there any FDA smartphone apps approved for SMI?**
Type: Knowledge Base (Clinicians)
Answered by: John Torous, MD, MBL, SMI Technology Expert - Harvard Medical School
Date Answered: February 27, 2019

<https://smiadviser.org>

Solution = Transparency

Trust	App co-design, full sharing and access to data, ability to delete data, remote consent built into the app	App and software support data security and privacy. Research conducted in a transparent and rigorous manner	Research conducted in ethical and transparent manner. App tools are shared to encourage research
Control	App co-design and iterative releases, ability for users to alter settings and nonfiction schedules	App data structured for access control. Users retain ultimate control of data	Personalized data collection matched to clinical needs. Ability to customize learning and interventions
Community	App, database, middleware, and data visualization code publicly available	App data shared with users. All methods and data processing code made publically available	App uses case and clinics designed to strengthen the therapeutic alliance between patient and clinician
	Transparent	Data Driven	Translational

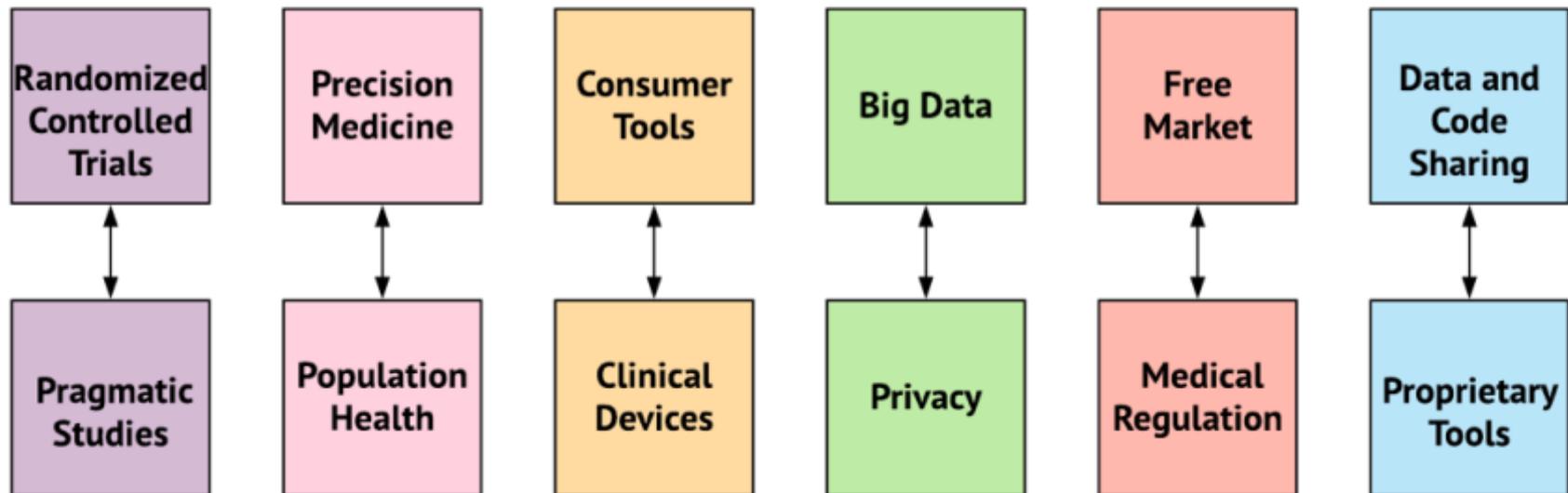


Torous J, Wisniewski H, Bird B, Carpenter E, David G, Elejalde E, Fulford D, Guimond S, Hays R, Henson P, Hoffman L. Creating a digital health smartphone app and digital phenotyping platform for mental health and diverse healthcare needs: an interdisciplinary and collaborative approach. Journal of Technology in Behavioral Science. 2019:1-3.



Solution = More Open Discussion

Dichotomies in the Development and Implementation of Digital Mental Health Tools



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Thank You



[Digitalpsych.org](https://digitalpsych.org) ; jtorous@bidmc.harvard.edu



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There are **two ways** you can give us your feedback:

1. Download the NAMI Convention App and rate the session in real time:

App Download Instructions

Visit your App Store and search for the “Aventri Events” app. Download the app and enter Access Code: 778151 or scan the following QR Code:



2. You can also evaluate the session on your computer. Go to: www.nami.org/sessioneval, select the session and click “Rate This Session.”