

CA may be a Red Squirrel



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If it is true, as we believe, that CA fills a deep social need & is resonant with a widespread hunger for authentic relationships, why is it that –with only a little exaggeration, we can say that a plurality –if not a majority– of the world’s active practitioners of the art are gathered in this room & that all the rest could join us in a room only a bit larger than this one.

It may be that Wolfensberger’s story of a profoundly dysfunctional society lacking the capacity to support the implementation of valid forms & principles is a sufficient explanation –though it implies that we should plan the memorial to observe the imminent extinction of the last few red squirrels.

Could there be other stories of Citizen Advocacy and community that are less vulnerable to becoming excuses for perpetuating ineffective practices by refusing to adapt to changing circumstances in an increasingly dismal environment?

Thinking both broadly & deeply
what are the trends that will have the most
influence on the lives of
people with DD over the coming 5-10 years?

The Promise: 1972

The answer to the parents' question, *Who will be there for our child when we are gone?*

A very substantial number (000s even 00,000s) of instrumental advocates & friend advocates who are...

...unpaid

...free from conflict of interest

...inspired & supported to hold high expectations & advocate for the most developmentally powerful services

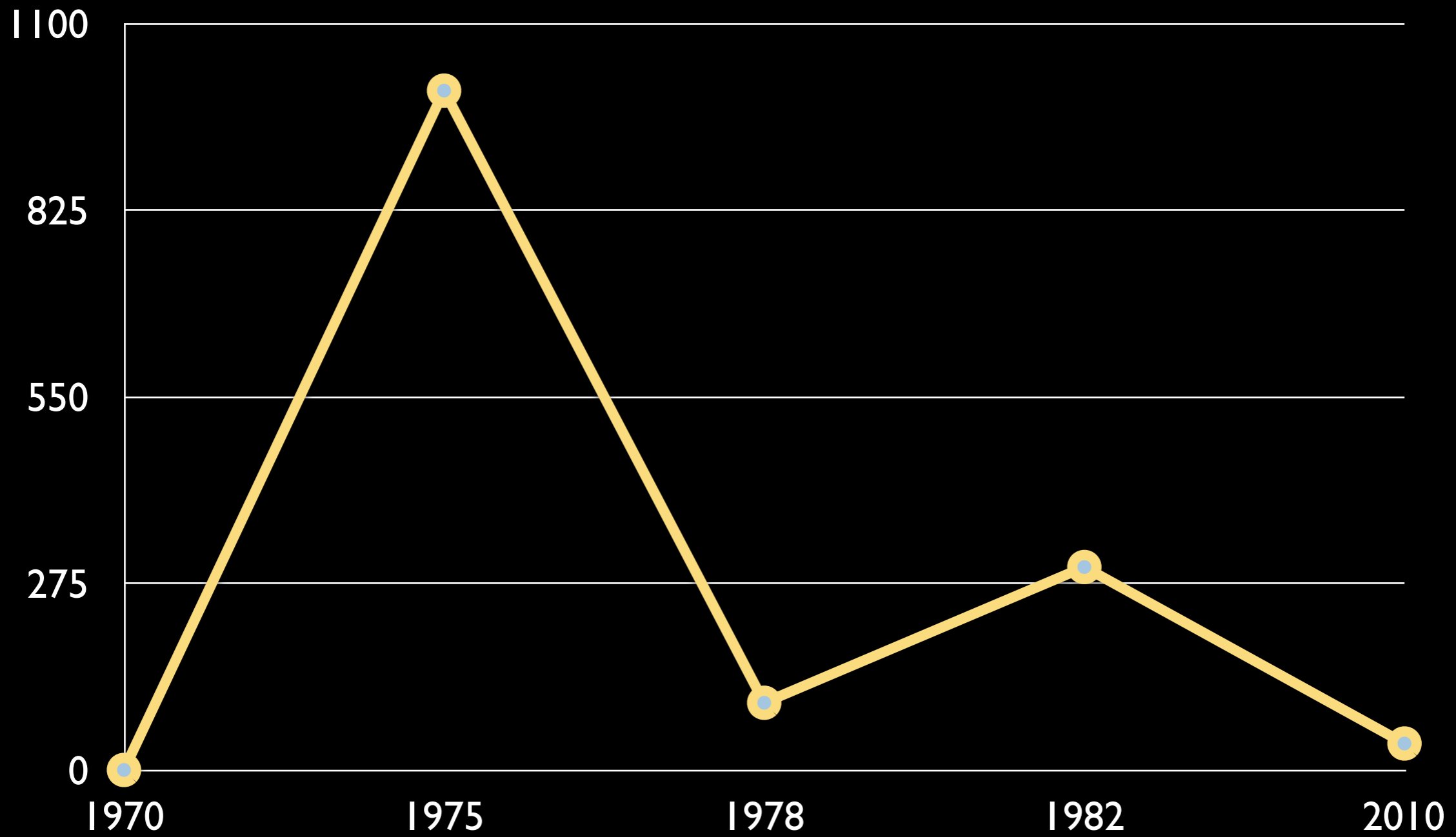
...filling a variety of roles & often acting as legal guardians or adoptive parents

The Promise: 1972

The answer to the parents' question, *Who will be there for our child when we are gone?*

Assumed

- ...most adults living in publicly funded residential services as part of a locally governed & funded, comprehensive community service system managed in conformity with the principle of normalization
- ...multiple and redundant safeguards
- ...strong local & state association acting as monitor, innovator & political power



Number of CA Programs*

*Approximations

The National P&A Promise: 1975

We will safeguard people who live in institutions, nursing homes & other facilities for people with developmental disabilities from abuse & neglect



GAO Promise: 1976

Individual

System

Internal



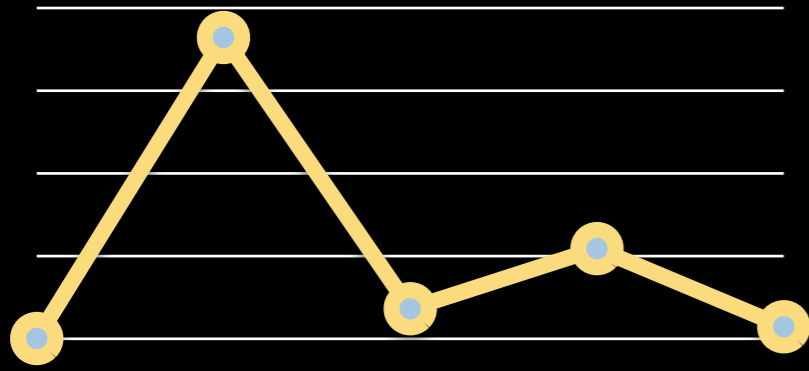
External



Balanced Multi-Component P&A Schema

GAO Promise: 1976

We will fulfill the National P & A promise in Georgia. Citizen Advocacy will mobilize many ordinary citizens of Georgia in personal relationships that will build the foundation for assuring that people in institutions & nursing homes are free from abuse & neglect (& have the support they deserve to live good lives in our communities)



Lessons that informed the Plan for CA in GA

Development will take time

Prime funding to communities to allow steady growth of local financial support & governance (this will introduce a manageable tension between CA practice & P&A requirements)

Encourage lower intensity relationships as well as high risk situations

Invest significantly in support & training for coordinators

Safeguard focus & fidelity

GARC + Atlanta ARC are well organized & powerful; GA has exemplary laws (though poor implementation & chronic underfunding)

Despite underfunding & weak central leadership, some local DD systems are growing stronger as part of a GAO supported network (#2 in integrated employment in US)

Benefits of comprehensive community services demonstrated & concepts persuasively articulated

Nationwide, growing momentum for de-institutionalization; vigorous debate

US Law (e.g. Sec 504 ('73) PL 94-142 ('75) DD Act ('75) & Federal Courts (Wyatt v Stickney, '73) add to momentum

GAO Promise: 1976

Assumptions that informed the
Plan for CA in GA

Least harm to people if P&A designation is lost
(some relationships will last even in the absence of
local offices)

CA resonates with GA's best cultural values & will
attract local support. Growing local investment from
multiple sources will establish financial independence
over time (10 years)

Build political constituency among valued citizens
unfamiliar with people with disabilities for policies
that will result in good local paid supports

Since 1976: A different world & the same CA*

Other safeguards compete with CA both practically (HIPPA) & paradigmatically

People & families have created rich lives at the margin of society (self-advocacy; special olympics): resilience to marginalization has taken many forms (sometimes aided by progressive service provision), this at least mitigates the degree of wounding that some people experience & provides pathways alternative to CA that may be more consistent with many current cultural values

Other inclusive innovations have disseminated more easily & been more widely adopted (worldwide if not in GA)

The “Third stage” has not emerged: parent advocacy has differentiated by diagnostic group; split over “cure”; largely failed to organize the 75%

SRV has lost influence: danger of self-sealing & loss of relevance

As a whole, CA not moved beyond a set of recurring issues: e.g. numbers remain small & rationals for slow growth remain stable; dependency on state P&A funds continues; impact on service delivery remains rare & reasons remain the same

*These changes are not, in themselves, reasons to reject faithful & consistent adherence to CA principles. They may however, go a ways toward explaining the red squirrel phenomenon. Though we did not explore this explicitly, it may also be that the Parsonian functionalism that Wolfensberger draws on, with its somewhat mechanistic background metaphors for social organization, makes a poor container for the tragic and ironic action involved in the day to day practice of CA.

GA's services are hard to move

DoJ victory has moved GA from 47th to 44th in fiscal effort among the states; success is measured in meeting numerical targets for congregate services & further strengthened centralized authority without SRV consistent central leadership

MA reform tends toward strangling the few personalized supports available in GA

Managed Care is coming

— *A Different World* —

What might we do more of, or do differently, if we want to redeem the promise of mobilizing ordinary citizens to press for service reform at a (local) systemic level?

(Experiment with suspending the rules if you like; notice if your even imagining an alternative is stuck in CA, SRV or Moral Coherency dogma*)

*"a principle or set of principles laid down by an authority as incontrovertibly true" OAD

A Different World

What might we do more of, or do differently, if we want to redeem the promise of creating adoptions?

(Experiment with suspending the rules if you like; notice if your even imagining an alternative is stuck in CA, SRV or Moral Coherency dogma*)

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CA Promise: 2013

