



# The ICADI Preparatory Workshop on Technology for Aging, Disability and Independence

June 26-27, 2003

The Royal Academy of Engineering

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of Engineering



# International Conference on Aging, Disability and Independence . . . ICADI Planning



June 2003



# Summary of this Presentation

- ? Planning objective and process
- ? Significance of the problem
- ? Background
- ? Needs and opportunities
- ? Strategy of approach
- ? Summary of recommendations
- ? Conclusion

# Aunt Millie



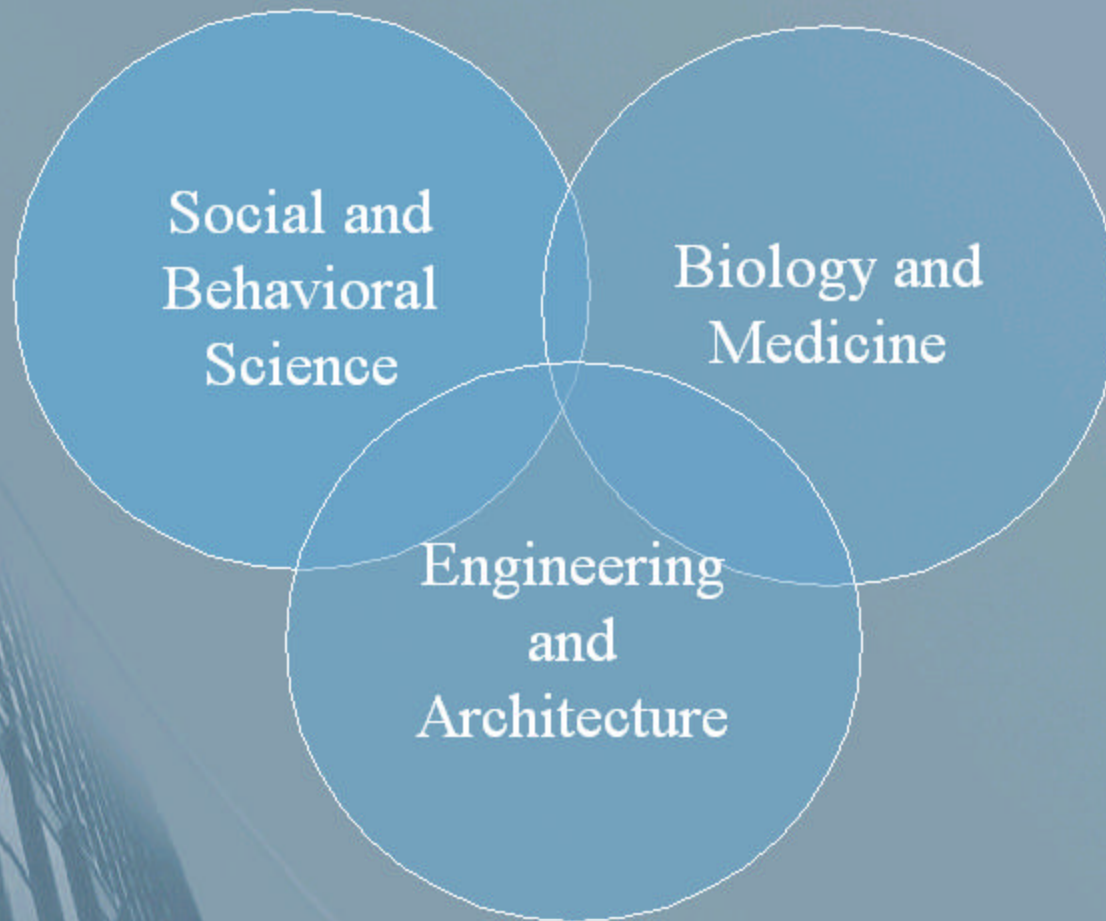
98<sup>th</sup> Birthday in 2003



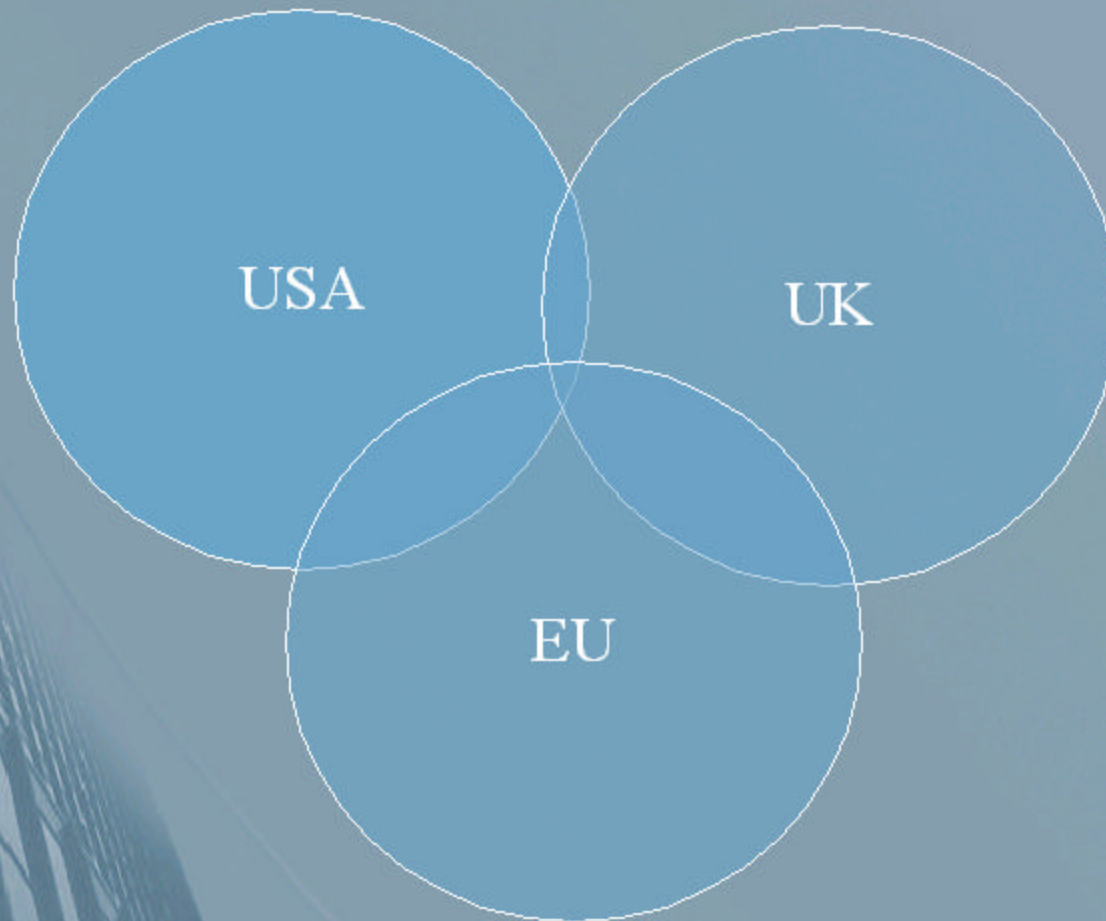
## Objective of ICADI

**Determine the technical requirements for better life quality of aging and disabled individuals by maintaining their independence and active participation.**

# Interdisciplinary Approach

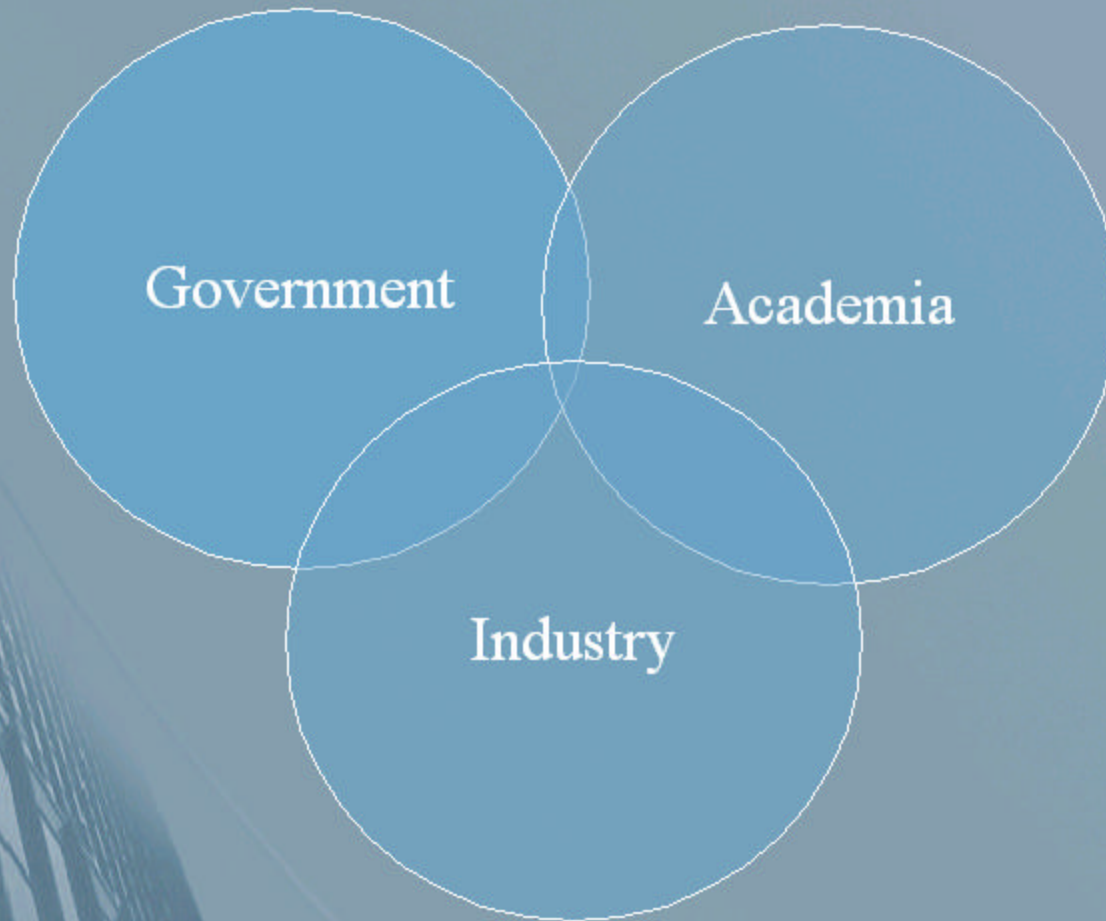


# International Approach





# Collaborative Approach





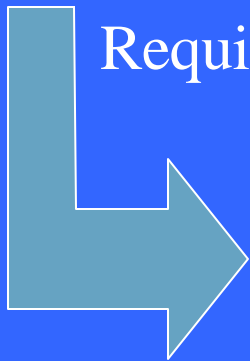
# Planning Process

Problem



Needs Assessment

Requirements



Design

Objectives



Intervention

Outcome



$\Delta$  = need - realization

Evaluation



# ICADI Technologies and Applications

1. Low Technology Assistive Devices
2. High Technology Assistive Devices & Environments
3. Consumer Perspective
4. Home Modification and Universal Design
5. Injury Prevention
6. Business Perspective
7. Transportation
8. Telehealth

# Current Approach

## Sponsor

## Program Objectives

?	NSF .....	?	Grants: IT, sensors, HCI, "science" emphasis
3.	EU .....	2.	IST, smart homes, assistive intelligent systems, accessibility
5.	UK EQUAL/EPSRC.....	3.	Multidisciplinary (MATCH) collaborative consortia, user focused, rehab technologies
7.	Industry.....	4.	Home health products; Telehealth; home security
9.	Other government agencies.....	5.	Regulatory; component technologies

# Vocabulary

- ? Telecare, Metastable people
- ? Home Healthcare
- ? Independent living; Independence
- ? Smart home
- ? Health telematics
- ? Routinisation
- ? Enablement, and many others

\* Need for precise definition of terms,  
preferably within a rigorous mathematical framework



# Overview

- ? Who?
- ? What?
- ? Why?
- ? How?
- ? Evaluation
  - Criteria for success

# Epidemiology of Aging and Disability

- ? Incidence and Prevalence
- ? Natural history
- ? Metrics and reporting
- ? Effect of interventions
- ? Trials and standards
  - Evidence; state of the science

# Health and Healthcare Challenges

## Economic Reality

- ? More than 14% of U.S. GDP is devoted to health care.
- ? Ratio of wage earners to seniors
  - 4/1 (now)
  - 2/1 (~2025)
- ? Average cost of assistive care
- ? \$60,000 / year / senior adult
- ? Seniors visit the doctor 6 x more
- ? often than younger people



## Demographic Trends

- ? The ratio of caregivers for at-home disabled will decrease from more than 20:1 down to less than 6:1 in 2030.

# Research and Development in Europe

## Demographics

Total EU population: 374 million

Over 60 years of age:

2003                    20%

2020                    25%

2050                    33%

Gunnar Fagerberg

London 26 June 2003



European Commission



Information Society

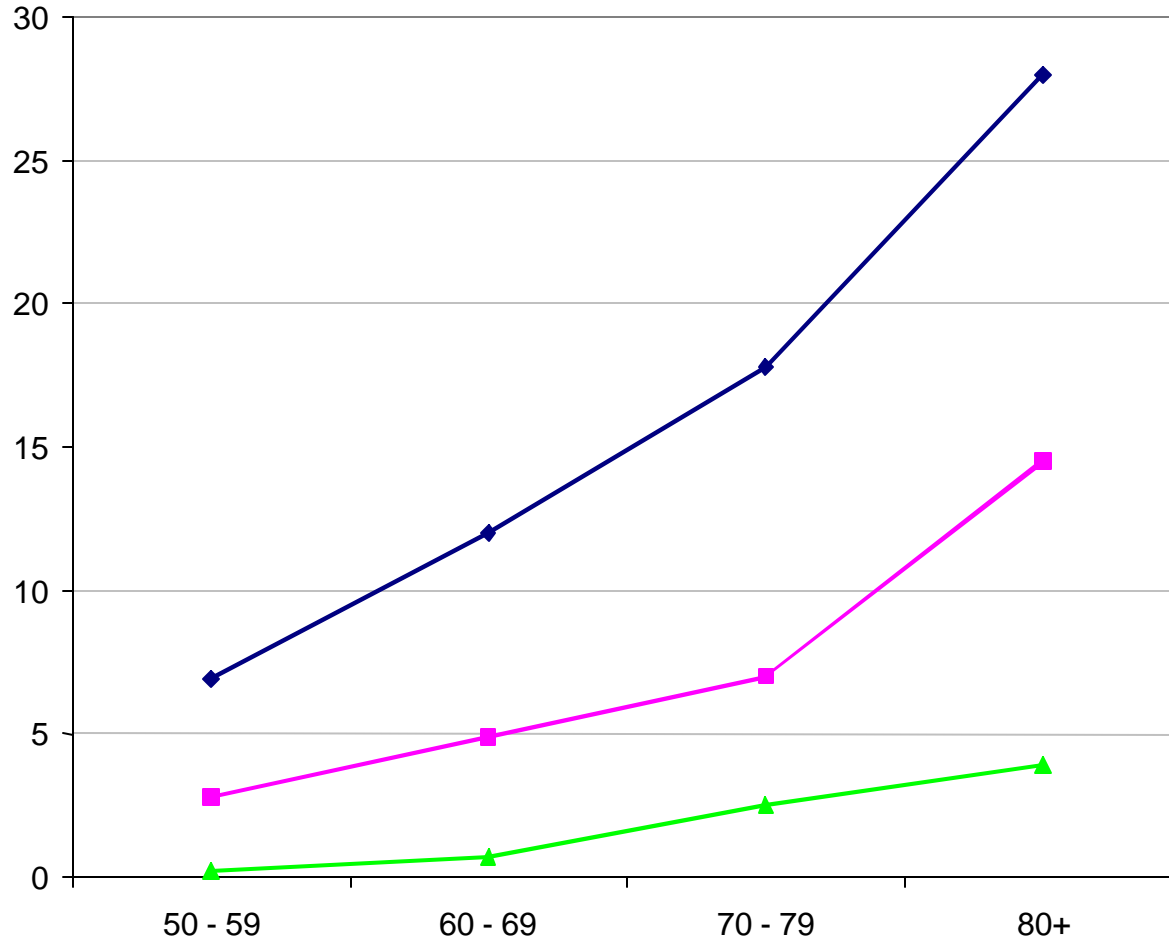


SIXTH FRAMEWORK  
PROGRAMME



# The European 'care gap'

Percentage of EU 50 population (2001)



... expressing a need for care

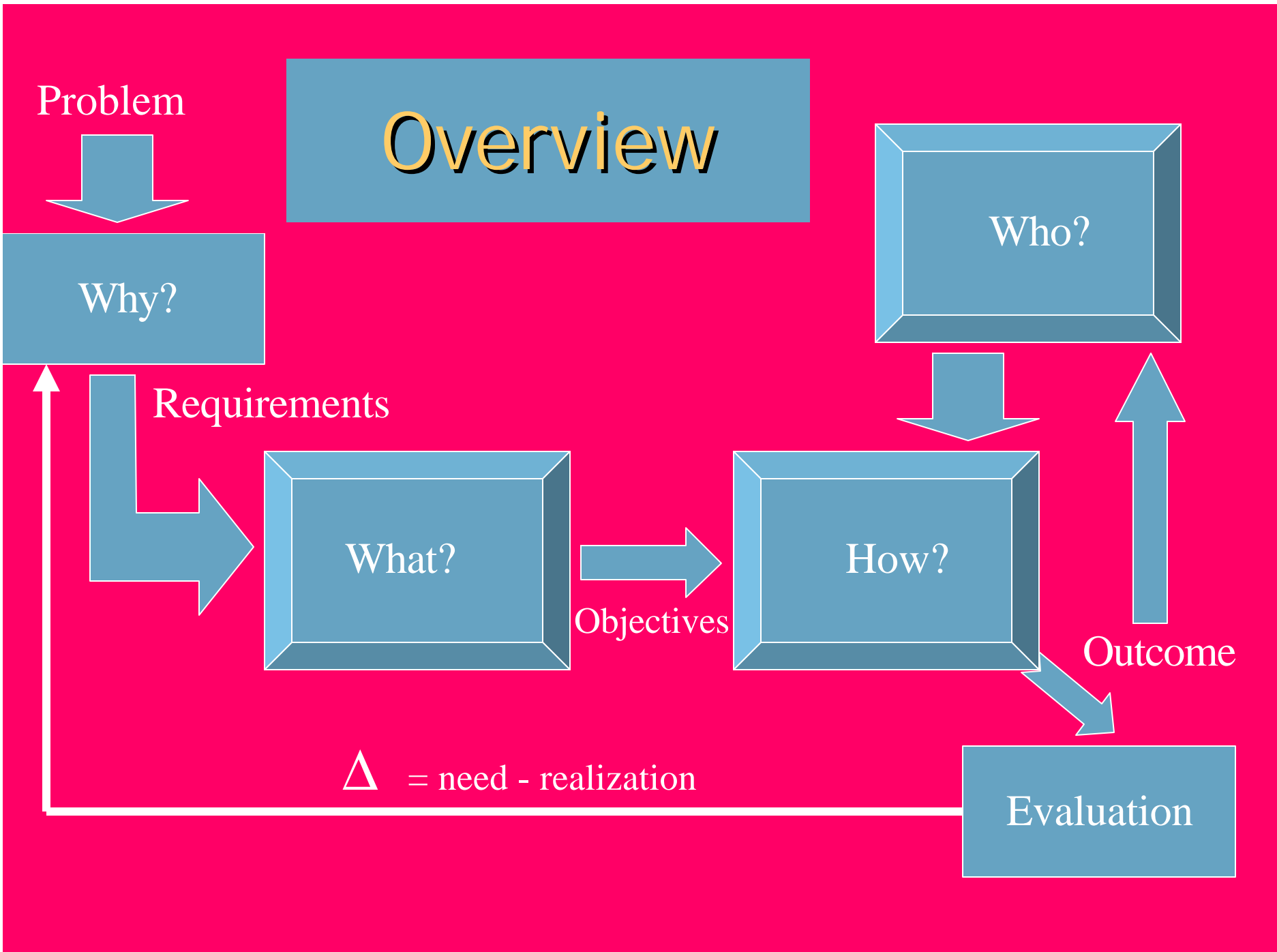
... actually receiving care

... thereof cared by professional service

Source: SeniorWatch, 2002

# Problem statement

Aging and disability are prevalent and potentially correctable sources of lost independence and diminished quality of life. Interventions produce variable outcomes that may be improved by assistive technologies. Improved life quality, increased independence, prevention of disease, lower cost of treatment, fewer complications and less variability in outcomes may be realized using appropriate technology.

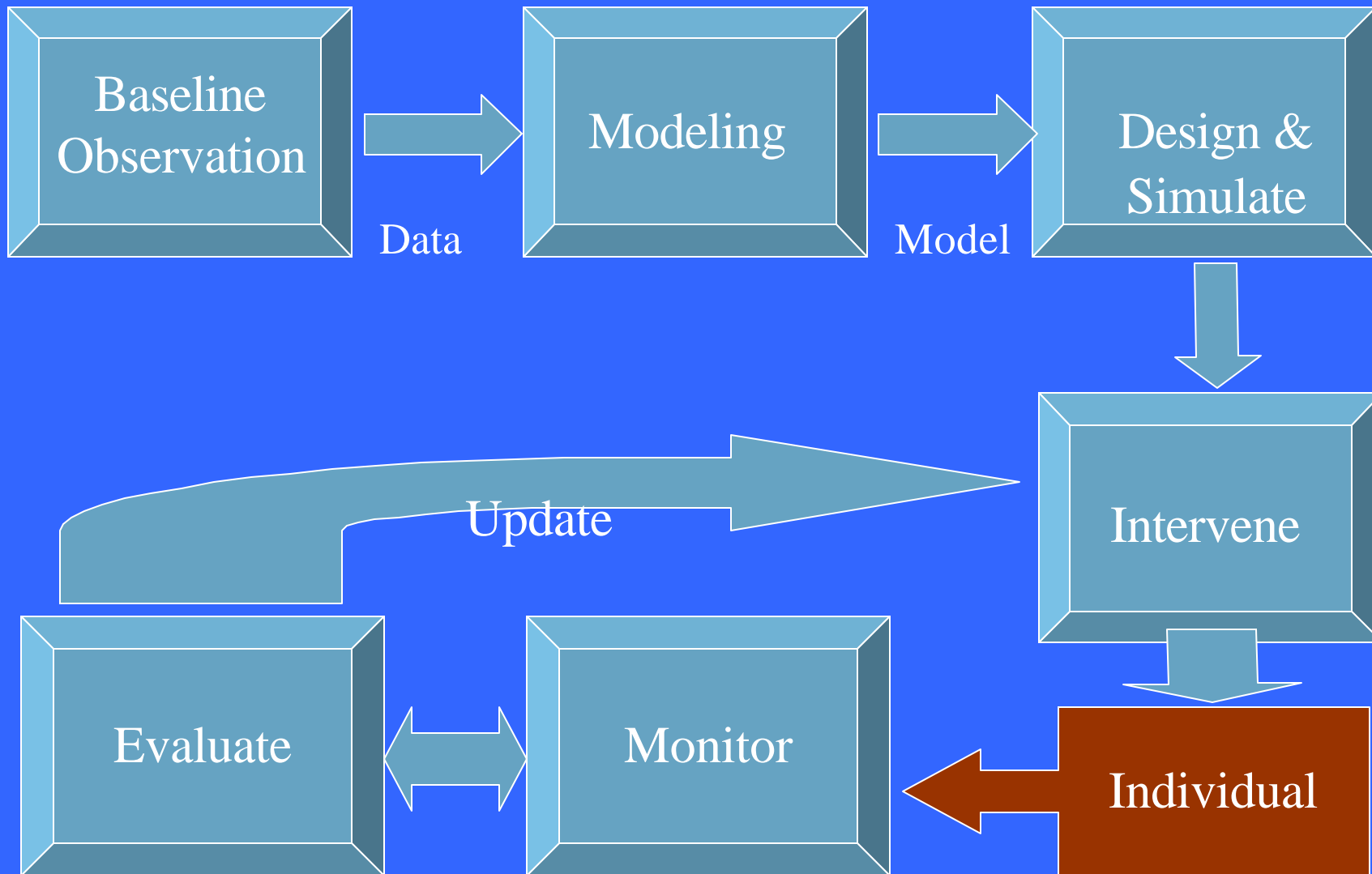


# Goals of International Conference on Aging, Disability and Independence (ICADI)

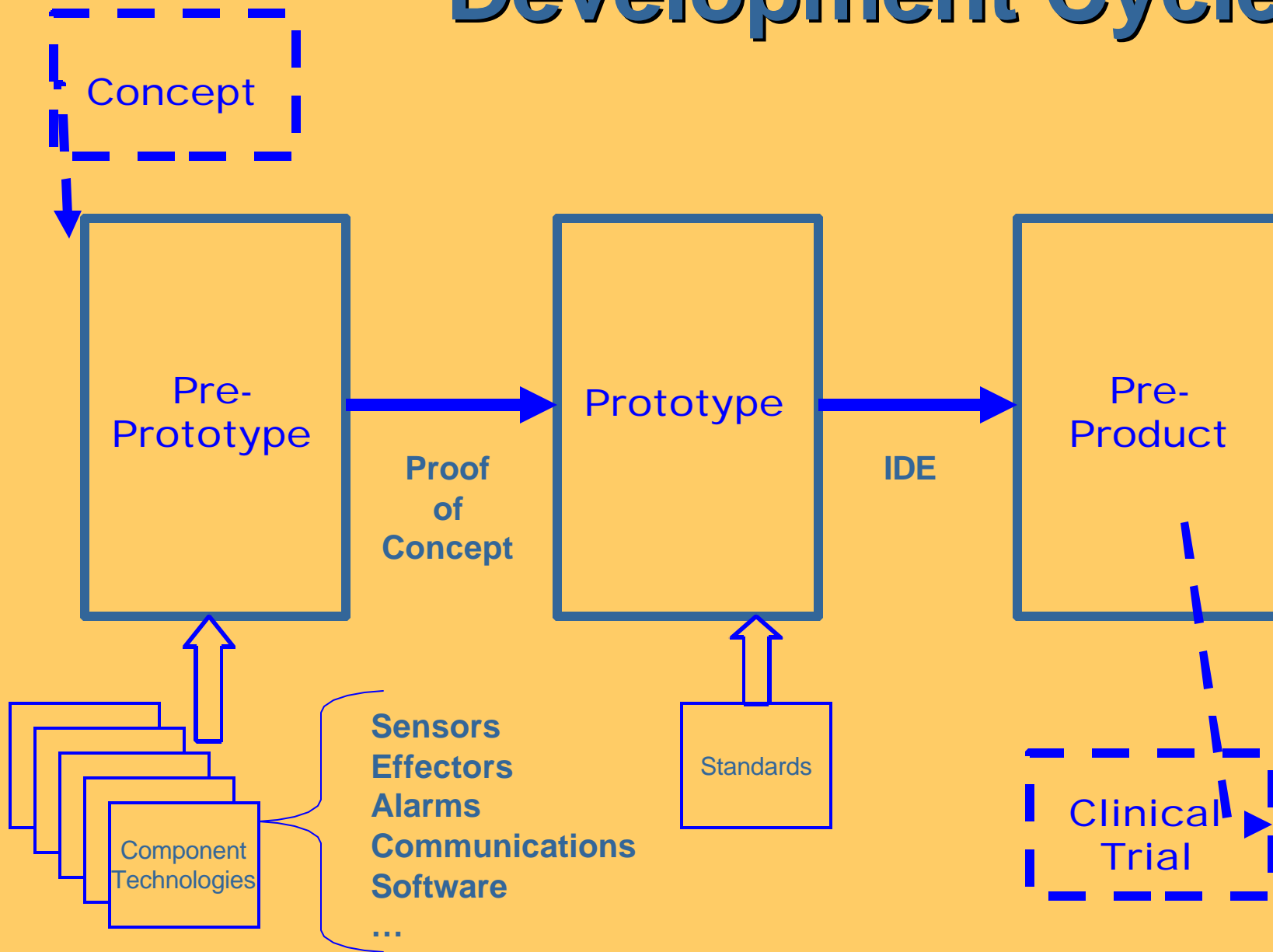
- ? Define needs
- ? Survey current and developing technologies
- ? Individualization to accommodate variability
- ? Optimize interventions
- ? Increase efficiency and efficacy



# ICADI Process



# Development Cycle



# Who?

- ? Many constituencies are affected by aging, disability and real or potential loss of independence

# Constituencies

- elders, disabled persons, and their families
- employers
- government
- primary care practitioner / attending clinician
- interventionalist: therapist or other (physical therapist, occupational therapist, nurse, chiropractor, ...)
- industry (medical device and supply)
- hospital administration or HMO
- 3rd party payor (health insurance company)
- general public; cancer/stroke/MI survivors; taxpayers



# Constituencies and Needs

- ? Who is affected by aging and disabilities?
- elders, disabled persons and their families
  - employers
  - government
  - primary care practitioner / referring clinician
  - interventionist / therapist
  - industry (medical device and supply)
  - hospital administration or HMO
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  - general public; cancer/stroke survivors; taxpayers

- ? What do they want?
- independence
  - rapid return to work
  - unrestricted activity
  - predictable outcome of therapy
  - most efficient use of resources, especially lowest cost
  - minimal side effects and complications
  - knowledge that a market is sufficient to assure positive ROI and profit (manage risk)
  - regulation to assure safe and effective devices

# Vision

- ? Appropriate technology improves outcomes while reducing overall variability, cost and complications. Benefits accrue to older and disabled individuals, families, payors, employers, and public at large.
- We can use resources more effectively and accommodate increased demands with same or lower cost using technology.
- New and existing technologies can be applied to fill the gap.

# Background

- ? Scope of aging and disability is vast
  - Potentially affects every member of society, either directly or indirectly, ...
- ? The population in US, UK and EU is aging, leading to growing demand
- ? There are latent and increasing needs that cannot be met by traditional means
- ? Technological intervention offers potential to meet evolving requirements

# Background (cont.)

- ? Function and disability are evaluated subjectively in most cases
- ? There are many technologies with overlapping and unique qualities
- ? There are several possible interventions for many conditions, so appropriate selection is required to match the solution with the need
- ? Interventions are not “standardized”
- ? Variability is high, but not well characterized
  - Individualization of interventions is essential



# Background (cont.)

- ? ICADI Systems must be flexible, adaptive, real time and interactive
- ? Full implementations are more useful than incremental ones
  - Full benefits may not be realized until a complete integrated system becomes available

# Broader Implications

- ? Technologies to monitor and assist in aging and disability are potentially useful for many other groups

# Broader Implications (constituencies)

- ? Frail elderly
- ? Medicare recipients
- ? Chronically ill
- ? Institutionalized
  - (demented patients, truants, young offenders, prisoners, soldiers, ...)
- ? High risk
  - (dementia, cancer, arthritis, heart disease/stroke, diabetes, depression)
- ? Hospice
- ? Rehabilitation / Recovery
- ? Mental illness and neurological disorders
  - (autism, substance abuse, obsessive-compulsive, schizophrenia, anorexia nervosa/bulimia, sleep disorders, phobias, sexual dysfunction, anxiety disorders)
- ? Space travelers
  - Space Station - Interplanetary travel
- ? Submariners

# Human-centered Technology Development

- ? Anthropometry
- ? Human factors
- ? Man-machine interfaces
- ? Workflow; time & motion analysis
- ? Human surrogates (robotics)
- ? Automobiles / aircraft (safety)
- ? Augmentation of human performance
- ? And Assistive technologies, rehabilitation research, and in the future, better human environments



# Defining the Problem

- ? Difficult to define and quantify, owing to lack of a controlled vocabulary, high variability (social, demographic, economic, ethnic, cultural, religious differences),
- ? Heterogeneity in populations is daunting
  - Requires large effect sizes to produce a measurable difference
  - Must know the variance to predict sample size
  - Subgroups defined by risk factors (which are themselves not well known)
- ? Shifting baseline - populations are mobile, especially urban. Lifetime employment at a single location is not the norm.
  - And the associated technologies are changing, as the need for them evolves



# Activity at every level

- ? Component technologies: electronic communications (wireless networks, pervasive computing); smart sensors; adaptive real-time interactive systems, embedded computers, MMI
- ? Population based measures
- ? Individual metrics
- ? Clinical trial design
- ? New measurement technologies; characterize human activity and performance in situ
- ? Mixing measurements and interventions
- ? Short time to market

# Background (cont.)

- ? Almost no quantitative information on system performance
  - lack of measurements make comparison of experience from various groups difficult
  - it is not clear that there is any “standard” way to treat the same disease between different groups
  - very high degree of variability and uncertainty
- ? Prognosis and “patient” selection are undefined or uncertain in many cases
- ? Outcomes are not well defined
  - non-technical and especially societal factors strongly influence the results

# Population-based Data (available now)

- ? Anthropometry (3D static with ROM)
- ? Demographics; Census
- ? Cost of healthcare (Medicare)
- ? Actuarial projections
- ? Disease epidemiology (especially reportable conditions)
- ? Death statistics
- ? Estimated loss of productivity

# Human Interest

- ? The Sims - popular software simulator of human interaction and environments
- ? Reality TV
  - Family living in 1900 home
  - Family living in frontier North American log cabin
  - The Osbornes
- ? The "Biosphere" project
- ? Utopian adult community at Disney properties in Kissimmee, FL



# Tasks

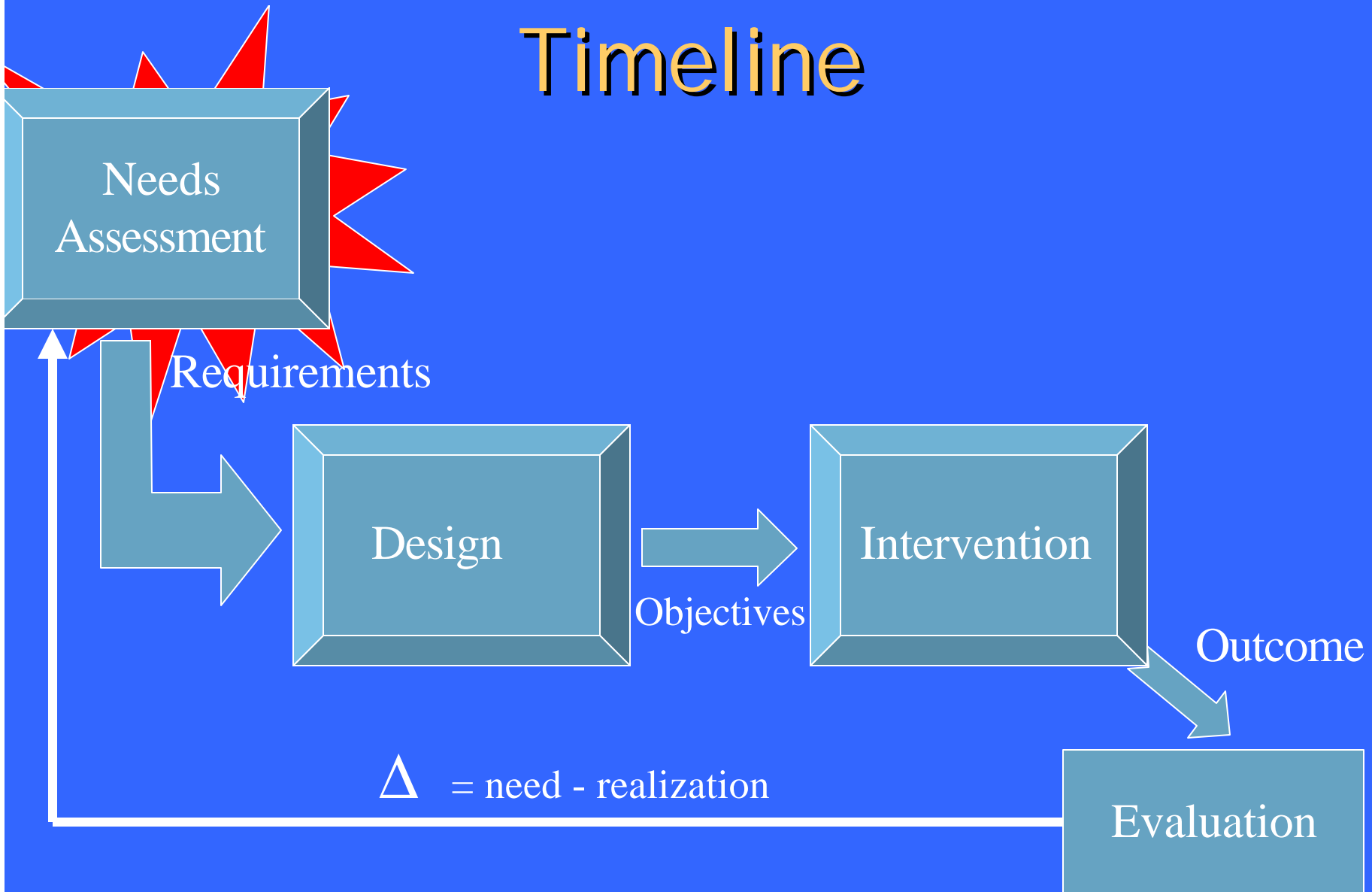
- ? Formal analysis of requirements with a well defined set of target specifications is essential for engineering
  - For example, \$100 per unit cost that monitors drug use and increases compliance with prescribed use (50% gain to 75+% total compliance that results in 30% reduction of unscheduled medical interventions)
- ? Glue grants: Where consortia are formed and funded, but their complete research agenda is not defined prior to sponsorship
  - Pays for information infrastructure; multi-institutional group of experts from diverse areas
  - 5 years of support
  - Example: cell signaling consortium (NIGMS glue grant)
  - Very large group participate (as an alternative to a geographically distinct local “Center”)
- ? CRM = Customer Relationship Management is used by industry to understand current customer requirements as they evolve over time



# Why?

- ? Needs assessment
- ? Current status of the field
- ? Opportunities
  - unmet needs
  - new technologies
    - ? Context aware computers, human centric computing, ubiquitous/pervasive computing,
    - ? Smart environments and sensors
  - many alternatives, which is best?

# Timeline



# Needs assessment

- ? Highly prevalent condition(s) with multiple presentations and etiologies
- ? Major costs to society when less effective and efficient treatment/intervention is used
- ? Many treatment options are available, but individualization (selection and outcome) are less predictable
  - Variability is high

# Variability

? Individual

? Disease

? Circumstances

? Device

? Operator

$\mathbb{P}$  need for individualization

# Barriers to wider use of ICADI Technologies

## ? Technology

- Does it work?
- Rapidly evolving
- Integrated systems not widely available

## ? Economic and Public Health Policy

- Cost
- Not specifically reimbursable in many cases
- Absent proof of benefit for most uses (experimental)
- Lack of randomized controlled clinical trials



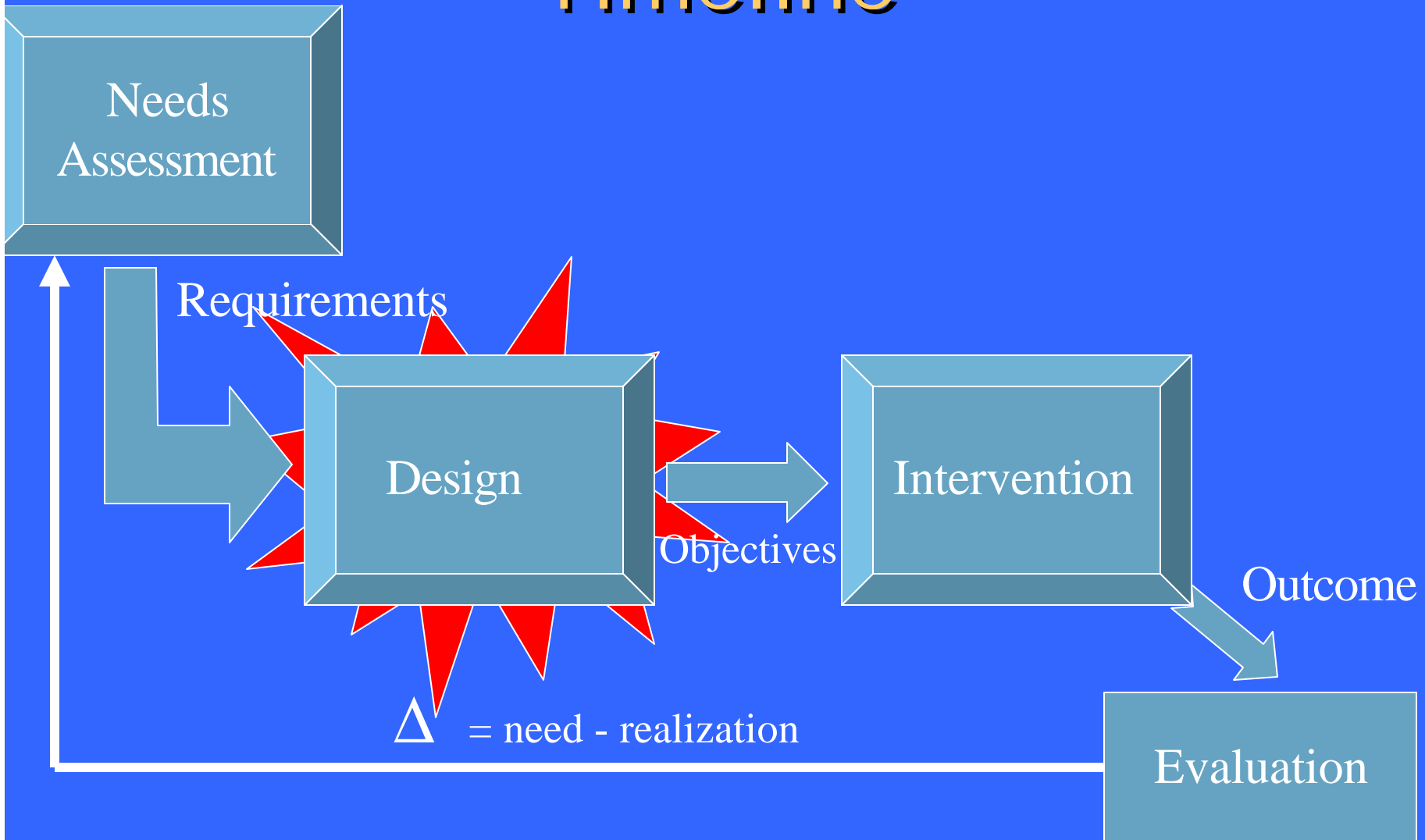
# Better outcomes are sought

- Immediate / short term
  - ? Reduced need for attendants / nursing
  - ? Rapid return to work
- Long term
  - ? Better Quality of Life
  - ? Lower overall disability
  - ? Maintenance of independence
- Economic / public health policy
  - ? Treatment outcome should be predictable
  - ? Reduce risk (effective prevention)
  - ? Minimize complications (safety)
  - ? Lower cost (to payor, government, employer, ...)

# Why? (in general)

- ? To reduce the variability in outcomes, total costs, and assure the best possible results with fewest complications in individual cases
- ? Most variability is due to a few sources
- ? Information overload

# Timeline



# What?

## ? ICADI Technologies

- Computing
- Sensors
- Service
- Design
- Smart appliances
- Interfaces
- Databases
- Tracking
- Robotics

# How?

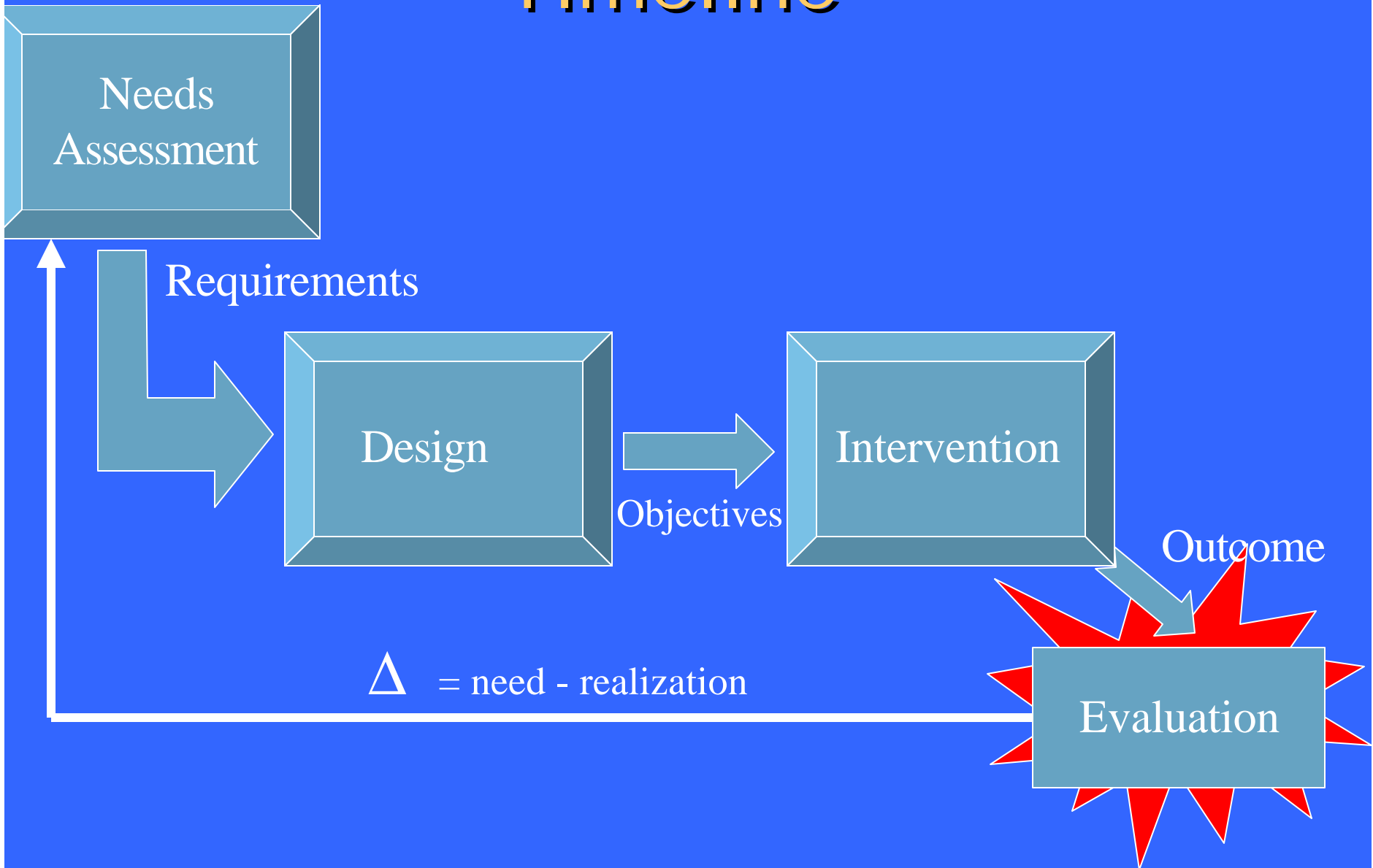
- ? Technology
- ? Processes / procedures (CPT)
- ? Experience and the value of expert knowledge
- ? Standard of care
- ? Regulatory
- ? Reimbursement



# Status of ICADI Technologies

- ? Smart home / environment testbed systems have been designed and can provide results to guide future development
- ? Numerous diverse technologies applied in this problem domain
- ? Need to review progress and plan for future
- ? A major driving force is emergence of new computing and networking technologies - context aware computing; ubiquitous / pervasive / embedded computers; wireless networks; innovative sensors
- ? Industry is interested and engaged

# Timeline



# Evaluation

## ? Process

- safer, faster, less expensive, preferable, more convenient, length of stay, ...
- formative: to develop questions; hypothesis generation
- summative: to address these questions and test hypotheses

## ? Outcome

- lower disability; greater “independence” =? satisfaction
- morbidity and mortality

# Quality

## Quality-fitness for use:

- ? “ The totality of features and characteristics of a product or service that bears on its ability to satisfy given needs. ”
- ? Determinants of Quality
  - design
  - ease of use
  - conformance to design
  - service

# Evaluation

## ? Process

- There are few data on the relative effectiveness and costs of treatments for aging and disability.

## ? Outcome (examples)

- Disability days: the number of days the patient was unable to perform work-related activities. (three types of "disability days"), AODL, QOLY, ...
- Measures include symptoms, function, general well-being, work disability, and satisfaction with care. Questionnaires with multilevel scales.



# Types of outcomes

## ? Technical outcomes

- success of procedure (completeness and integrity of data, responsiveness, QoS)

## ? Patient oriented outcomes

- disease specific outcome
- generic outcome

# Technical (process) outcomes

## ? procedure-related

- System functionality; usability; responsiveness; up-time

## ? device-related

- Sensitivity
- Signal-to-noise
- Reliability

# Patient oriented outcome measures

? disease or region specific -

- focus symptoms in one particular region of the body or that are affected by one particular disease

? generic -

- examine a number of general domains
- tend to be better validated (and more reliable)
- results can be extrapolated across disorders to make comparisons of diseases, interventions
- SF36, McGill, ... for example

# Disease specific tools

- ? Validated for specific disorder or region of the body
- ? Advantage is that these parameters will generally be most responsive to intervention
- ? For aging and disability:
  - Range of motion; gait
  - Oral intake; urinary output

# Generic measures (for FDA, NIH projects)

## ? Relevant measures

- functional status (physical, emotional)
  - ? SF-36

## ? Pain

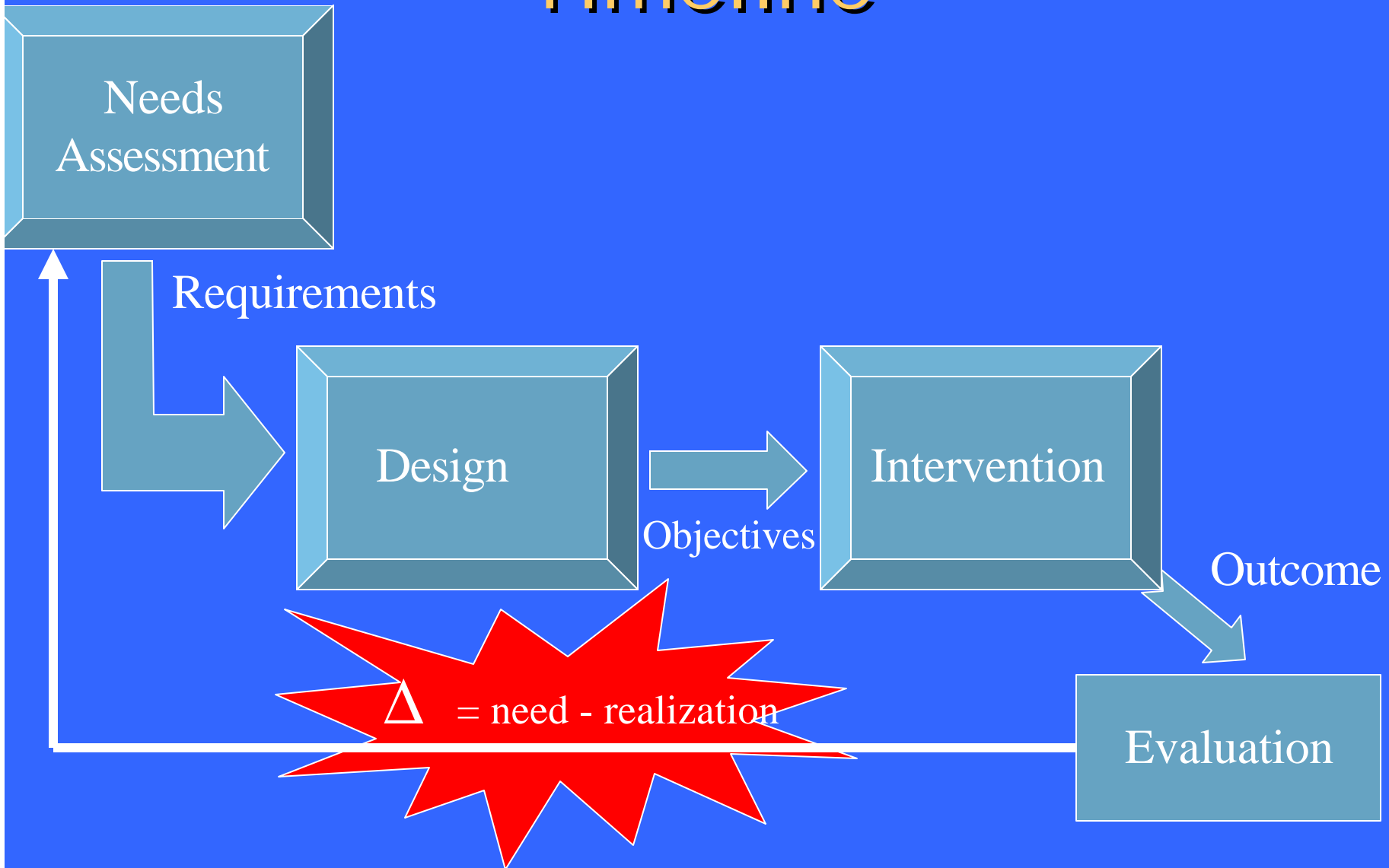
- McGill
- VAS (visual analog scale, Lykert)

## ? Quality of life (QOL)

- SF-36
- Euroqol



# Timeline



# Risks (pitfalls)

- ? Seductive nature of new technologies
  - Lead to implicit or explicit exaggerated claims
- ? Technology may not be ready; unreliable, inaccurate
- ? Users not trained (pilot error)
- ? Users won't accept the system (e.g., decline to use it)

# More Risks

- ? Multiple suppliers - integration introduces unforeseen problems
- ? Manufacturers exit and don't support their products
- ? Unintended use of technology
- ? Not reimbursable
- ? Inadequate quality control
- ? Failure to obtain informed consent; privacy; security; confidentiality

# Criteria for success (evidence)

- ? acceptance by individuals ←MOST important
- ? efficacy and efficiency
- ? morbidity and mortality
- ? Quality of Life
  - Activities of daily living; independence
- ? user satisfaction
  - Would you do it again?
  - What would you be willing to pay for?
  - Preference - Given alternatives, what can you do without?

# Regulatory Requirements

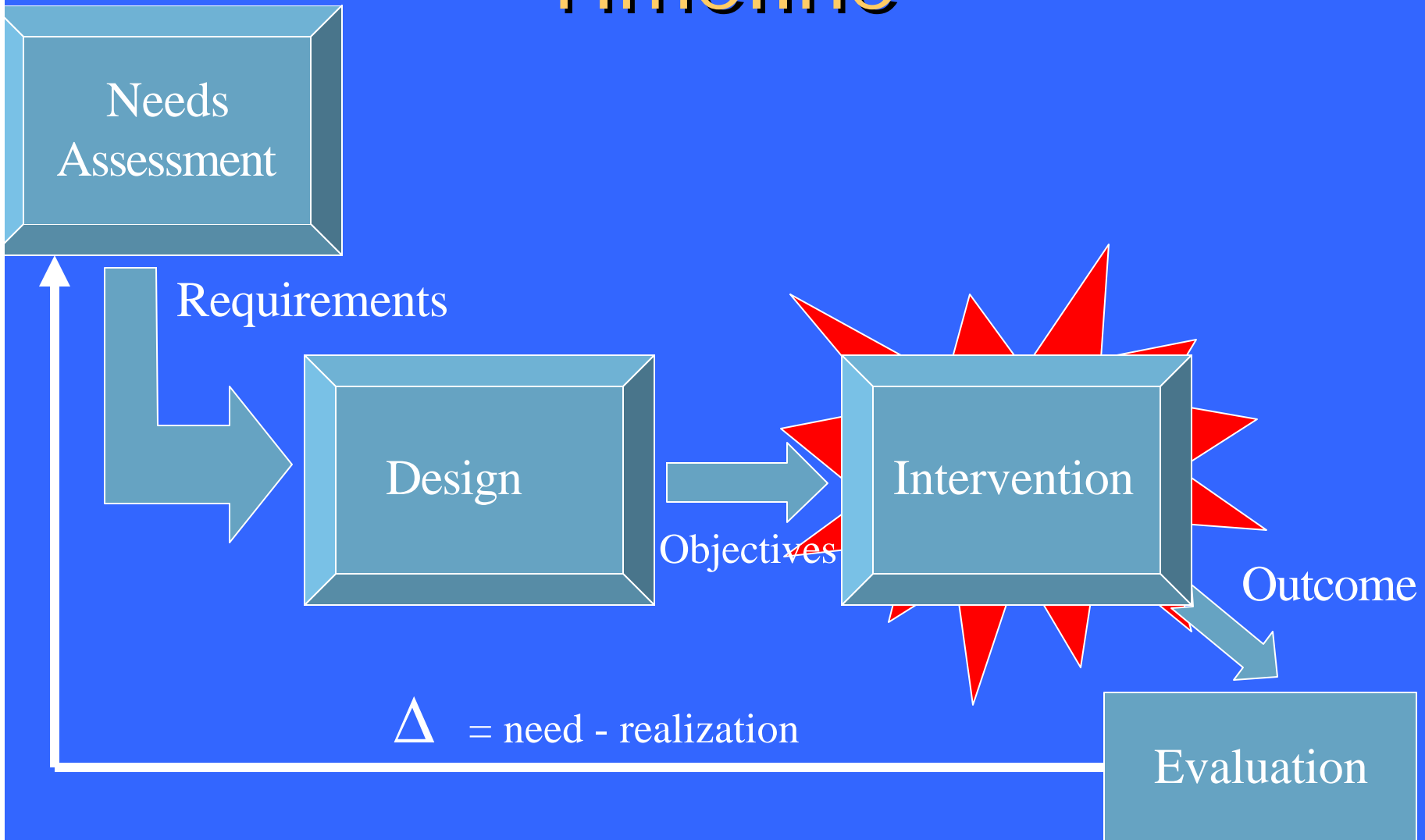
- ? FDA oversight
  - safety and efficacy must be proven
  - approval does not assure reimbursement
- ? Quality control
- ? Performance standards
  - not yet defined



# Reimbursement Requirements

- ? Cost-benefit analysis
- ? Proof of cost efficacy
- ? CPT - ICD match
  - best to use existing codes
- ? Independent verification of performance
  - randomized controlled trials
  - multiple centers

# Timeline





# Summary of Recommendations

- ? Natural history is not well characterized (variability); evidence of benefit is limited; standard of care must be modified
- ? Uncertain market - Who will pay for this?
- ? Evaluation of needs and outcomes are needed
  - standards, metrics, regulatory, reimbursement
- ? Multidisciplinary training opportunities
- ? Academic/industrial/government consortia; international cooperation and collaboration are important



# Summary of Recommendations

- ? Natural history is largely unknown; evidence of benefit is limited; standard of care must be modified
- ? Uncertain market - Who will pay for this?
- ? Evaluation of needs and outcomes are needed
  - standards, metrics, regulatory, reimbursement
- ? Multidisciplinary training opportunities
- ? Academic/industrial/government consortia; internationalism
- ? ICADI is timely - and can help meet critical and immediate needs of aging and disabled through appropriate technology

What else do you want to know?

