





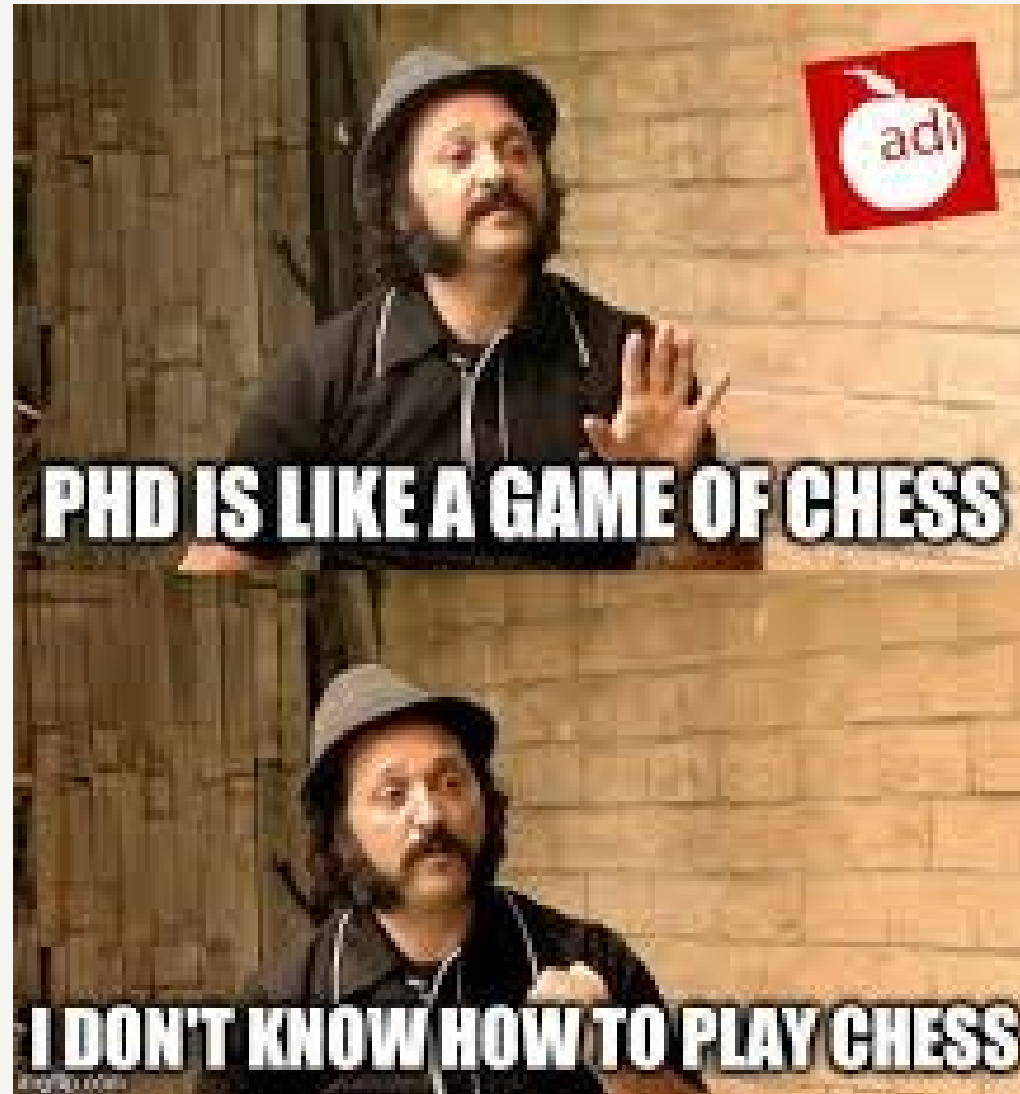
Giulia Ferrazzi

Tecnico della Riabilitazione
Psichiatrica, Analista del
Comportamento, iscritta a SIACSA
(ABAIT) - BCBA[®]

Dottoranda in Neuroscienze c/o
Università di Modena e Reggio Emilia.

Il mio dottorato ha come focus il
Progetto di Vita delle Persone
Autistiche Adulte.





Ci siamo posti una domanda...anzi più di una

COME È FATTO? COSA CONTIENE? QUALI SONO GLI ELEMENTI
IMPRESCINDIBILI?

Progetto Di Vita (PdV)



Dipartimento per il programma di Governo

Focus

Politiche in materia di disabilità

(D.lgs. 62/2024)

Con il decreto legislativo n. 62/2024 si è introdotta la definizione e la disciplina del progetto di vita, attraverso il quale la persona con disabilità può costruire, insieme all'unità di valutazione multidimensionale, i sostegni di cui necessita per vivere i vari contesti di vita (abitativo, lavorativo, sportivo, ecc.).

L'elaborazione del progetto di vita deve:

- partire dai bisogni, desideri ed aspettative della persona;
- prevedere un coordinamento dei vari interventi (tra Pei scolastico e progetto educativo extrascolastico, tra interventi sociali ed inclusione lavorativa, ecc.);
- essere dotato di un ben definito budget di progetto, in cui si individuano sia le risorse economiche che professionali e strumentali per sostenere l'attuazione del PdV

Identificare le evidenze sui principali strumenti di valutazione nello sviluppo di PdV per persone autistiche.





National Library of Medicine
National Center for Biotechnology Information

PubMed[®]



Scopus 20

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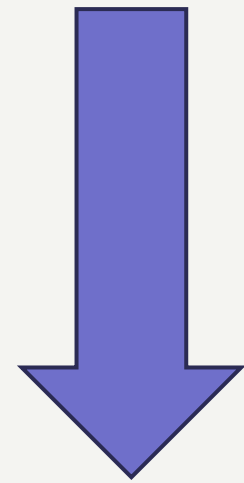
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APA PsycInfo[®]

The premier abstracting and indexing database covering the behavioral and social sciences from the authority in psychology.



Progetto di Vita
PdV



Person Centered Plan
PCP

Person-Centered Plan (PCP)

Review article

The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review

V. Ratti^{a,*}, A. Hassiotis^a, J. Crabtree^b, S. Deb^c, P. Gallagher^d, G. Unwin^e

^a University College London, Division of Psychiatry, 6th Floor Maple House, 149 Tottenham Court Road, London W1T 7NF, United Kingdom

^b Tower Hamlets Community Learning Disability Service, Beaumont House, Mile End Hospital, Bancroft Road, London E1 4DG, United Kingdom

^c Imperial College London, Department of Medicine, Centre for Mental Health, 7th Floor Commonwealth Building, Hammersmith Hospital Campus, Du Cane Road, London W12 0NN, United Kingdom

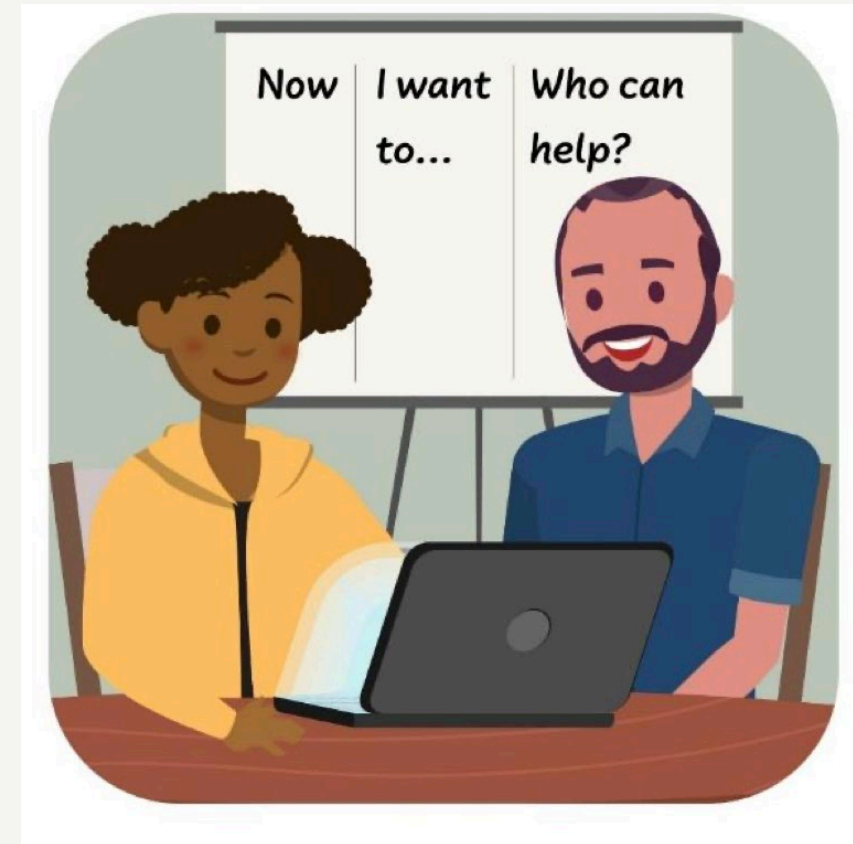
^d Camden and Islington Foundation Trust, St Pancras Hospital, 4 St Pancras Way, London NW1 0PE, United Kingdom

^e University of Birmingham, School of Psychology, Frankland Building, Edgbaston, Birmingham B15 2TT, United Kingdom

Il Person-Centered-Plan (PCP) è definito come un processo di selezione e organizzazione dei servizi e dei supporti di cui una persona con disabilità può aver bisogno per vivere nella comunità (McCausland et al 2022).

Il PCP permette alla persona **di fare scelte informate** su come vuole vivere la sua vita, ora e in futuro. Sostiene la persona identificare i propri sogni, **desideri e obiettivi** e ciò che è necessario per renderli possibili.

Il PCP è rivolta a tutti, indipendentemente dal livello di assistenza o supporto di cui hanno bisogno.





Progetto di Vita
PdV

Person Centered Plan
PCP

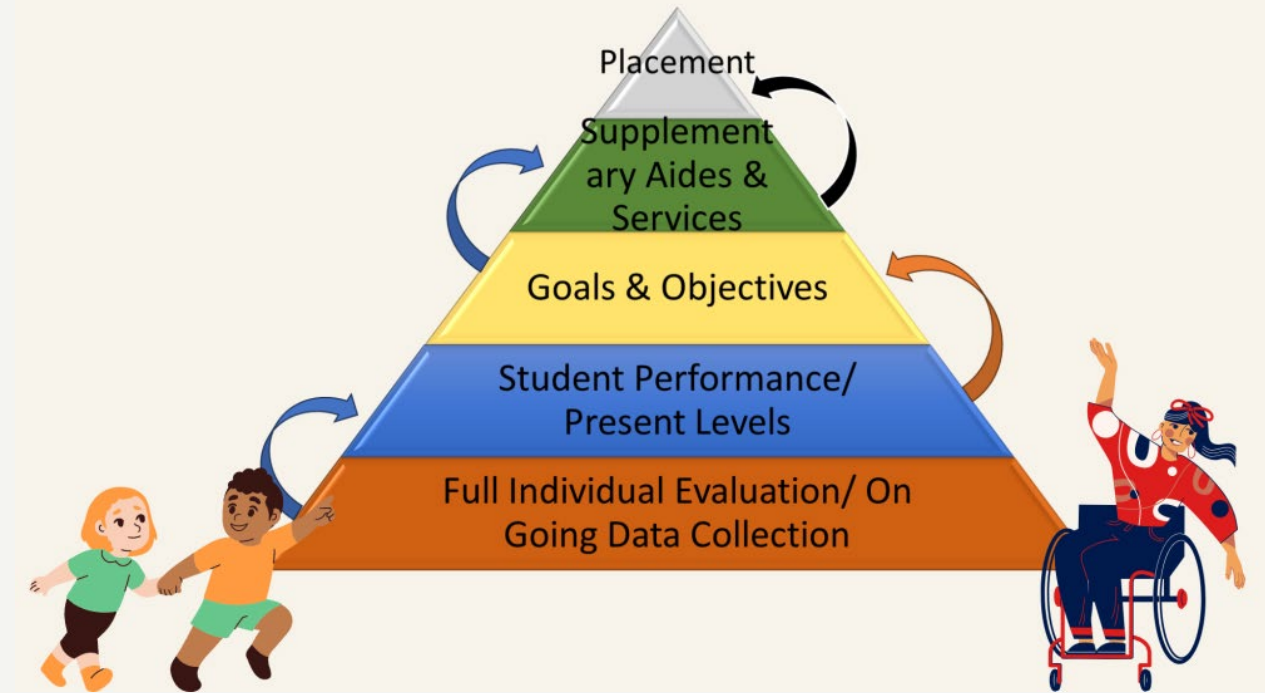
Individualized Education Plan
IEP

Individualized Education Plan (IEP)

This is a plan or program developed to ensure that a child with an identified disability who is attending an elementary or secondary educational institution receives **specialized instruction and related services**.

Incentrato sulla scuola e sul mondo del lavoro (Hughes et al 2023).

Educate Yourself The IEP is built Block by Block



Published in final edited form as:
Pediatrics. 2023 July 01; 152(1): . doi:10.1542/peds.2022-060199.

Individualized Education Programs and Transition Planning for Adolescents With Autism

Michelle M. Hughes, PhD^a, Anne V. Kirby, PhD^b, John Davis, PhD^c, Deborah A. Bilder, MD^d, Mary Patrick, MPH^a, Maya Lopez, MD^d, Leann S. DaWalt, PhD^e, Elise T. Pas, PhD^f, Amanda V. Bakian, PhD^b, Kelly A. Shaw, PhD^a, Monica DiRienzo, MA^a, Allison Hudson, BS^d, Yvette D. Schwenk, MS^d, Thaer M. Baroud, MHSA^d, Anita Washington, MPH^a, Matthew J. Maenner, PhD^a

^aNational Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia

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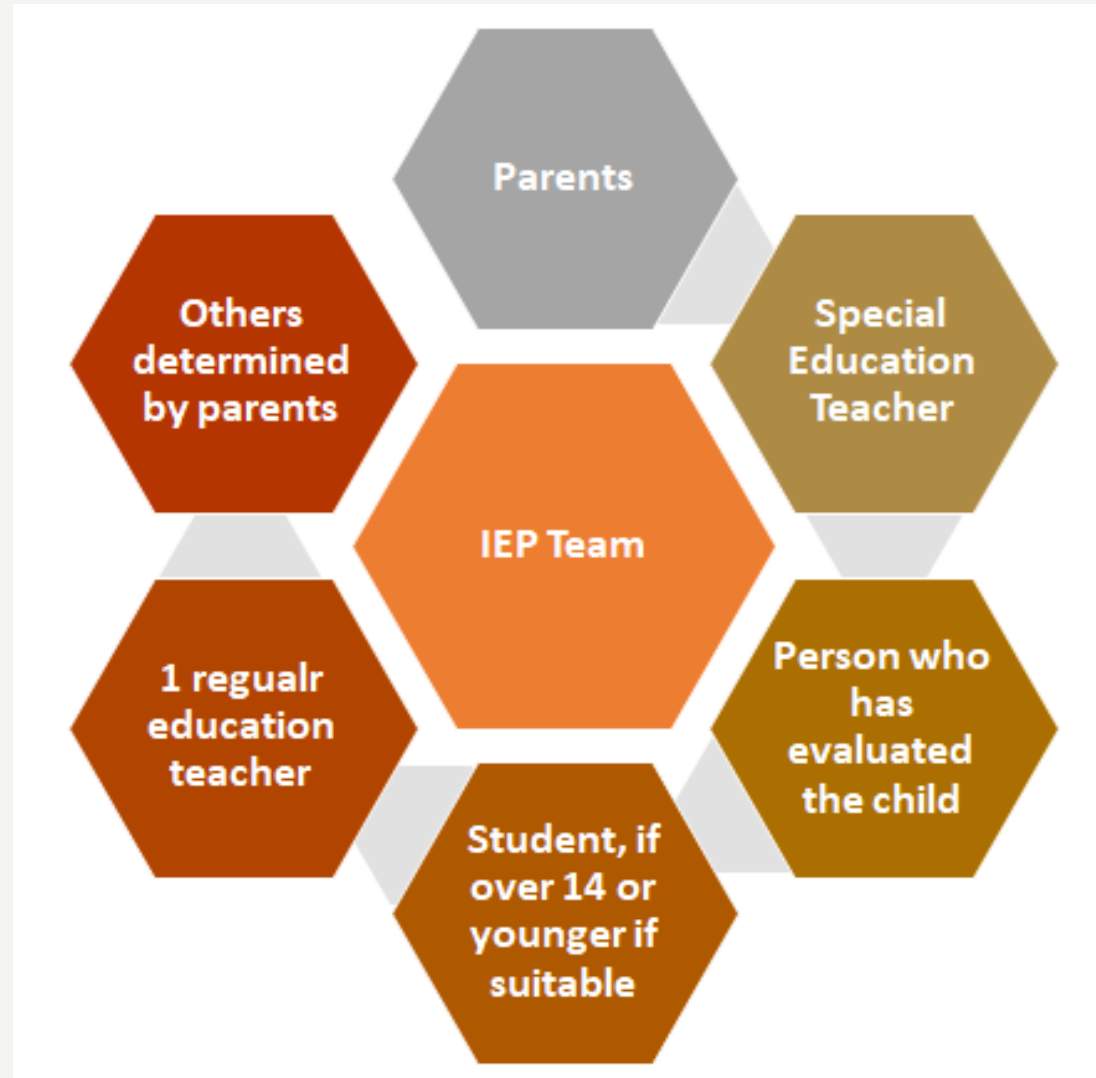
^cUniversity of Texas at San Antonio, San Antonio, Texas

^dUniversity of Arkansas for Medical Sciences, Little Rock, Arkansas

^eUniversity of Wisconsin, Madison, Wisconsin

^fJohns Hopkins Bloomberg School of Public Health, Baltimore, Maryland

IEP team



Piano di Transizione Vs Progetto di Vita

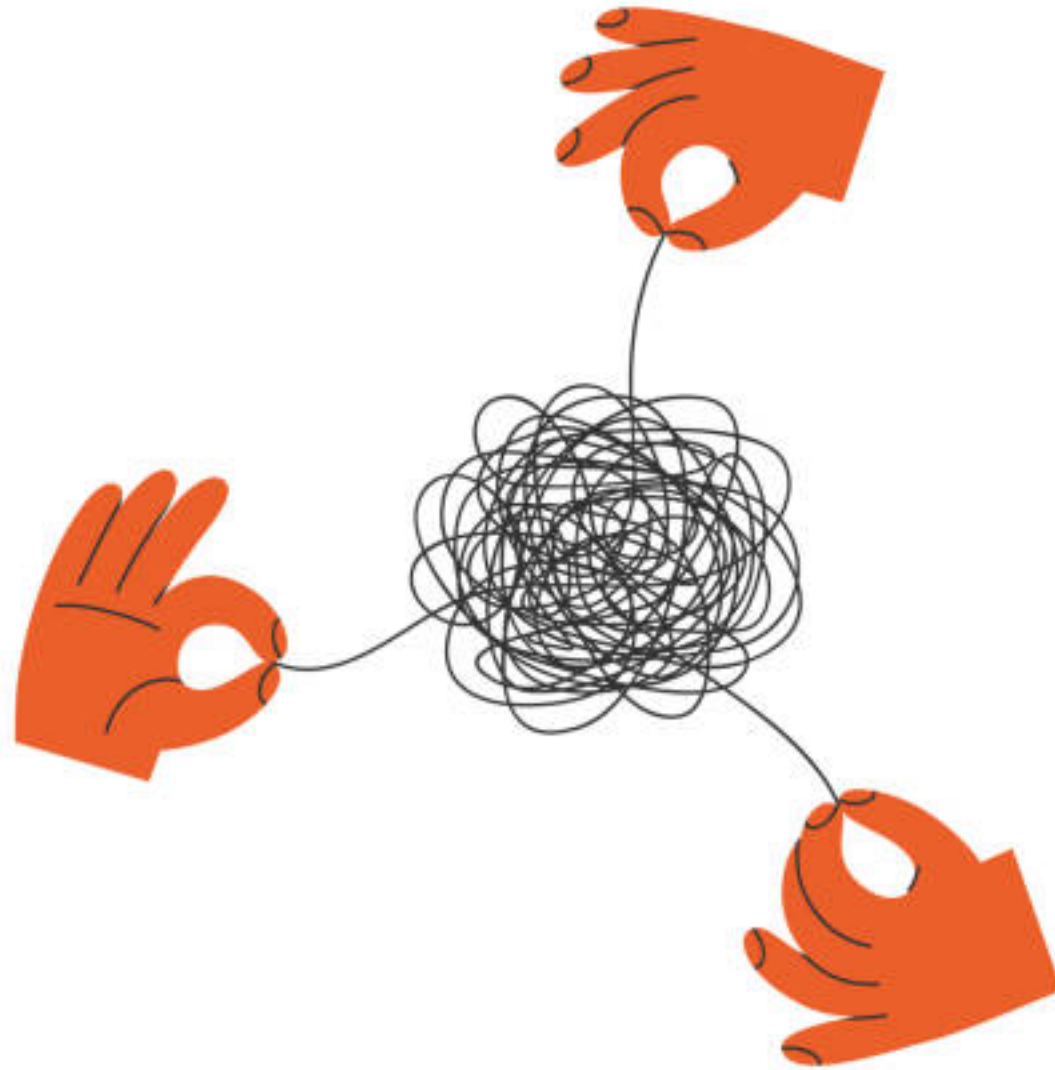
Definitions of Transition

Several definitions exist to describe transition. In its simplest term, Transition is defined by the process of which the total care of children and adolescents with chronic medical conditions is transferred to the adult teams. Carrizosa et al defined Transition as “a purposeful, planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents and young adults with chronic medical conditions, as they advance from a pediatric and family-centered to an adult, individual focused health care provider” [1]. Healthcare transition is defined by the American national alliance to advance adolescents healthcare as the process of changing from a pediatric to an adult model of health care [2].



THI I PERS

Serafino Co
Laura Gall



ersal Design ilities

Silvia PAVESI^a
20133, Italia

Metodologia – PRISMA-ScR



Quesito

- Identificare le evidenze sui principali strumenti di valutazione nello sviluppo di PdV per persone autistiche.

Stringa di Ricerca

- Ricerca su database
- Pubmed, Psychinfo, Embase, Scopus, Cynhal e Web of Science

Selezione per titoli ed abstract

- Rayyan

Lettura dei full text

Inclusione

Criteri di Inclusione

Inclusione

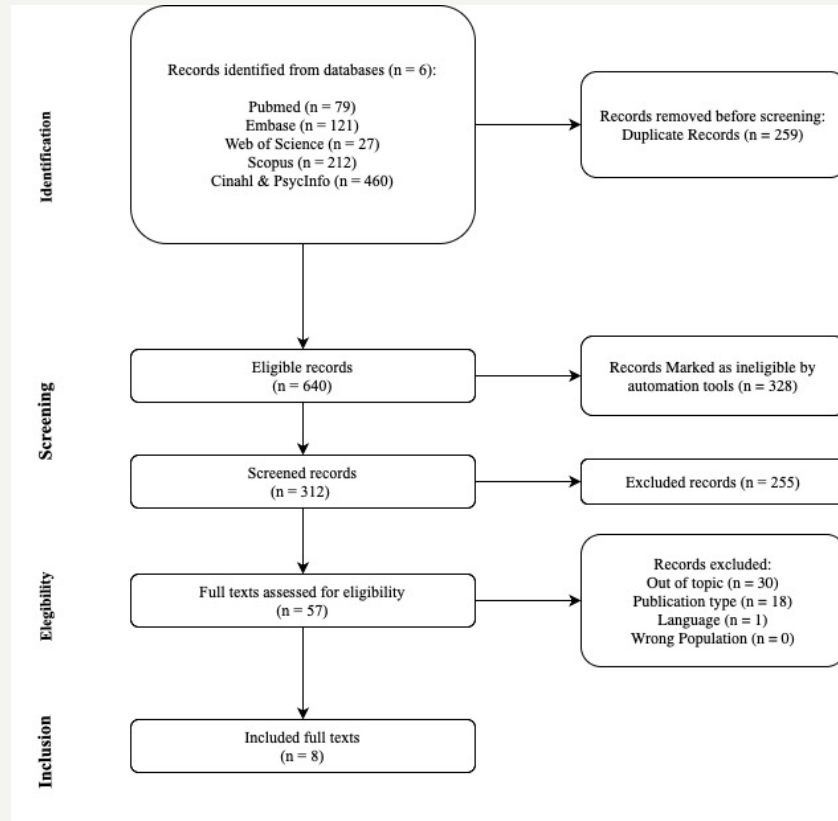
Incentrati sullo sviluppo di PdV (o PCP) per persone di qualsiasi età con diagnosi primaria di ASD

Venivano esplicitati gli strumenti utilizzati

Lingua Inglese

Pubblicazioni peer-review

Materiali e Metodi



Database	Search Strategy 11 th April 2024
EMBASE	('life plan' OR 'personal development plan' OR 'life roadmap' OR 'person-centered plan*' OR 'support plan*' OR 'transition plan*' OR 'life project') AND 'autism'/exp
Web of Science	"Life Plan" OR "Personal Development Plan" OR "Life Roadmap" OR "Person-Centered Plan*" OR "Support Plan*" OR "Transition Plan*" OR "life project"
SCOPUS	"life plan" OR "personal development plan" OR "life roadmap" OR "person-centered plan*" OR "support plan*" OR "transition plan*" OR "life project" + "autism" OR "autism spectrum disorder"
Cinahl & PsycInfo	("Life Plan" OR "Personal Development Plan" OR "Life Roadmap" OR "Person-Centered Plan*" OR "Support Plan*" OR "Transition Plan*" OR "life project") AND ("Autism" OR "Autism Spectrum Disorder")
Pubmed	("Life Plan" OR "Personal Development Plan" OR "Life Roadmap" OR "Person-Centered Plan*" OR "Support Plan*" OR "Transition Plan*" OR "life project") AND ("Autism" OR "Autism Spectrum Disorder")

Risultati

1

Tutti studi
pubblicati dopo il
2000.

2

Studi
descrittivi/narrativi
un solo studio con
una metodologia
mista

3

Natura
contestualista del
progetto di vita

4

Due studi italiani,
Sei studi Americani

Bui et al, 2003 - East Meets West: Analysis of Person-Centered Planning in the Context of Asian American Values

Individual Service Design (Forest & Pearpoint, 1992)

Personal Futures Planning (Mount & Zwernick, 1988; O'Brien, 1987)

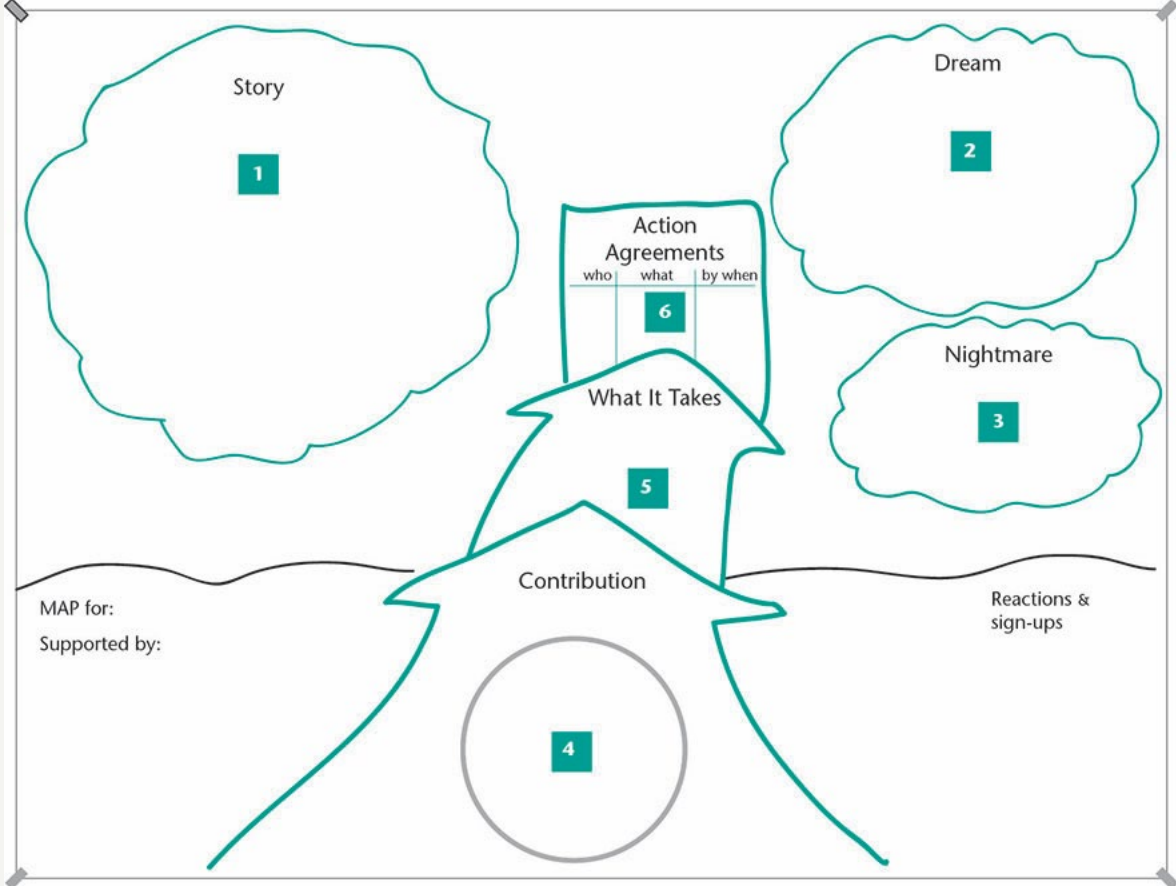
Essential Lifestyle Planning (Smull & Harrison, 1992)

Whole Life Planning (Butterworth, Hagner et al., 1993)

McGill Action Planning System (Forest & Pearpoint, 1992; Vandercook, York, & Forest, 1989)

PATH (Forest & Pearpoint, 1992; Pearpoint & Forest, 1998)

Group Action Planning (Blue-Banning et al., 2000; Turnbull & Turnbull, 1996)



VALORI

Modifications of Person-Centered Planning for Asian American Families

Don't

Do

Establishing a relationship

Assume that all Asian American families think and act the same.

Find out about the family's level of acculturation, date of immigration, socioeconomic status, and resources.

Assume that all Asian American groups are the same between and within Asian subgroups.

Familiarize yourself with some of the family's cultural values and behaviors.

Show up at the family's home unexpected.

Try to get a formal introduction to the main authority figure in the family by a respected third party.

Meeting logistics

Expect the family to meet during work hours or too often.

Meet at times that are convenient for the family (once per month).

Meet at a location that is far away from the family's home.

Arrange for transportation and babysitting if necessary.

Assume that the family can comprehend or speak English.

Bring an interpreter if the family has limited English proficiency.

Communicating during the meeting

Insist on equal participation immediately.

Address questions and answers to the main authority figure.

Expect families to disagree with you openly.

Pay attention to your verbal cues and the family's non-verbal cues.

Push the families to tell their stories before they trust you.

Give family members sufficient time to become comfortable with you before they tell their stories.

Share any information with outsiders.

Ensure that all discussions are confidential and private.

Rush the family into making quick decisions.

Give the family members time to make decisions in private.

Callicott, 2003 - Culturally Sensitive Collaboration Within Person-Centered Planning

Un gruppo di persone scelte dall'individuo che partecipano attivamente alla pianificazione e al supporto. Include familiari, amici, insegnanti, operatori sociali e membri della comunità.

TABLE 1
Essential Components of Person-Centered Planning

Component	Description
Circle of support	<p>Elaborates the types of relationships a focus individual has for developing support systems</p> <ul style="list-style-type: none"> • Involves listing the network of available persons in concentric circles from closest to the individual outward • Typically a team would use 4 circles. <ul style="list-style-type: none"> ○ The first circle would be intimate friends, family. ○ The second circle would be good friends. ○ The third circle would be people, organizations, or teams with which the focus person participates. ○ The fourth circle would be paid service providers.
Making Action Plans (MAPS; Alper & Ryndak, 1992; Forest & Pearpoint, 1992)	<p>Designed to graphically depict future visioning and plan accordingly</p> <ul style="list-style-type: none"> • Involves answering eight questions and depicting the process on large sheets of paper, typically with representational graphics or drawings <ul style="list-style-type: none"> ○ What is a MAP? ○ What is this person's history or story? ○ What are the person's dreams? What are the person's nightmares? ○ Who is the person? ○ What are the person's strengths, gifts and talents? ○ What does the person need? ○ What does the ideal day look like or what is the plan of action?
Planning Alternative Tomorrows with Hope (PATH; Pearpoint, O'Brien, & Forest, 1993)	<p>Extends MAP to address capacity building</p> <ul style="list-style-type: none"> • Step 1: Identify "the dream." • Step 2: Create short-term goals (6 months to a year). • Step 3: Describe current status. • Step 4: Enroll supportive people to assist. • Step 5: Recognize the "cost" of participation and gather commitment. • Step 6: Visualize the progress that will have happened in 3 months. • Step 7: Visualize the progress 1 month from now. • Step 8: Identify the first thing to be done.

Brainstorming per costruire una visione condivisa del futuro dell'individuo. Si concentra su obiettivi a lungo termine, punti di forza e desideri personali.

Uno strumento grafico per visualizzare e pianificare un futuro positivo. PATH aiuta a identificare le mete e le azioni necessarie per raggiungerle, con un focus sull'individuo.

Path (Planning Alternative Tomorrow with Hope)

PATH Template

Describe the Now
 Invite Enrollment
 Decide to Get Stronger
 Agree to Next Steps
 Organize the next months work
 Identify

23.6.20

My PATH

Now

- 15 yrs old
- Live with Mum, Dad + Sister
- Home schooled
- Go to dance Lessons once a week
- Need to learn to be more independent
- SLEEP!**
- feel good + confident

SIGN UP...

Me
 Mum
 Dad
 Sister
 Grandma
 Grandad
 Auntie
 Uncle
 Jo (from Zoo club)

STAYING STRONG ACTIONS

- * Animals - going to visit Grandma's dog
- * Family - do lots together, Good at talking about worries
- * Photography along the river
- * Talking to Auntie on facetime
- * Cuddles

POSITIVE & POSSIBLE

- Aug Entered NT photo competition
- Royal Observatory Visit
- Dec Cook some dinner with Grandma
- Nov do paintings of my photos for presents
- July Keper for the day at the zoo
- Homeschool lessons at zoo
- Sept - Dec work on a project about stars
- Summer finish photo club

SAFARI HOLIDAY

- with family
- see animals in the wild
- photographs

DISNEYLAND

Zoo Keeper

Nature photographer

our house

- live near the beach
- do our house work
- cook meals

Me + Sister

"Be more independent"

Astronomy

gentle | sensitive | precise

Caring | great imagination | sense of humour

"A REALLY POSITIVE EXPERIENCE"

"I'm excited for you... a fulfilling future"

"So proud of the person you are"

Awesome

Cappa et al., 2020 Network of services facilitating and supporting job placement for people with autism spectrum disorders. The experience of the ASL Piacenza, Italy

Autonomia del progetto di vita con focus sulle possibilità lavorative.

Internship program (lavori manuali, ripetitivi)

Cooperativa Sociale (diversa varietà di proposte)

IPS - Individual Placement and Support (dedicata a persone livello 1)

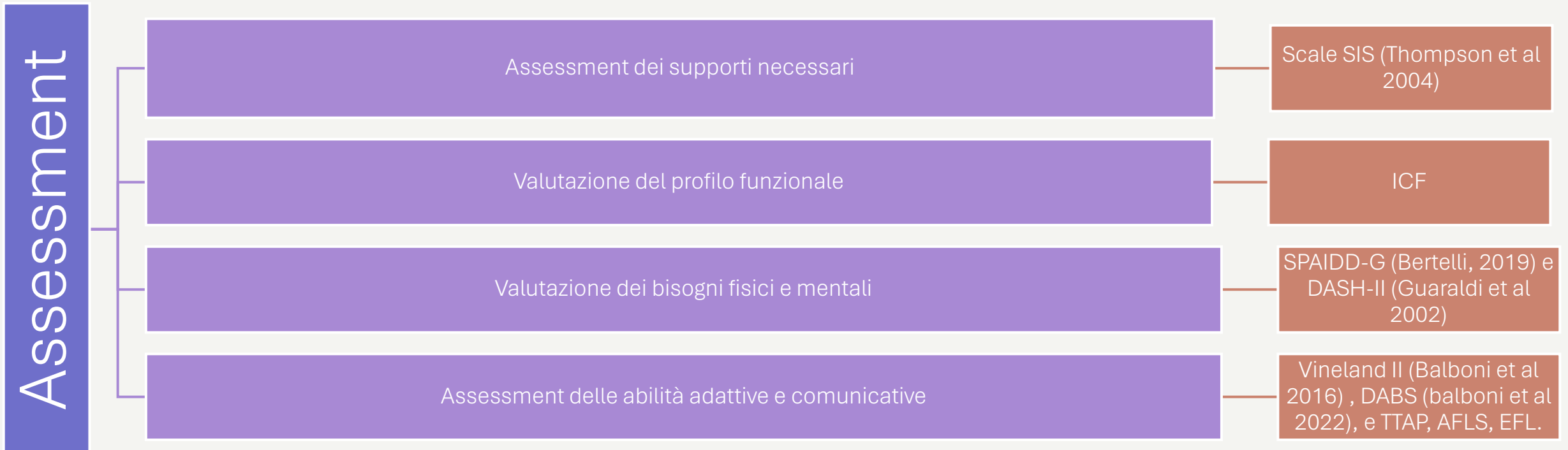


Corti et al, 2023. The Life Project of People with Autism and Intellectual Disability: Investigating Personal Preferences and Values to Enhance Self-Determination

Il **bilancio ecologico** è un modo per recuperare quella dimensione che deve essere assolutamente presente nel progetto di vita della persona che è rappresentata dagli **outcome personali**, di ciò che è importante per la persona.



Strumenti nel PdV



Hagner et al 2014 - Person-Centered Planning for Transition-Aged Youth with Autism Spectrum Disorders

- Unico studio dove con parte descrittiva insieme ad una parte sperimentale (47 studenti –USA).
- Una maggiore partecipazione è associata ad un miglior outcome in termini abilitativi.
- Le strategie che facilitano la partecipazione includono:
 - (1) la preparazione individuale preparazione individuale agli incontri,
 - (2) attività informali per costruire un rapporto tra il facilitatore della pianificazione e il giovane ,
 - (3) la flessibilità delle riunioni,
 - (4) la partecipazione a distanza e
 - (5) il sostegno a mezzi di comunicazione alternativi.

How Person-Centered Was This Planning?
24 domande. Valutazione da 2 a 0. Punteggio >20 (PCP centrato sulla persona)

Focalizzazione sui desideri e obiettivi personali della persona
Incorporazione dei punti di forza della persona
Partecipazione attiva della persona.
Inclusione di membri significativi del supporto naturale
Considerazione dei bisogni culturali e individuali
Enfasi sulla qualità della vita
Pianificazione per l'inclusione sociale
Enfasi sull'autodeterminazione
Definizione di obiettivi concreti e raggiungibili
Riconoscimento delle barriere e strategie per superarle
Uso di linguaggio rispettoso e positivo
Monitoraggio continuo e revisione del piano

69% delle persone hanno un PCP centrato sulla persona.

Kim et al, 2004. Transition to Adulthood for Students With Severe Intellectual Disabilities: Shifting Toward Person-Family Interdependent Planning

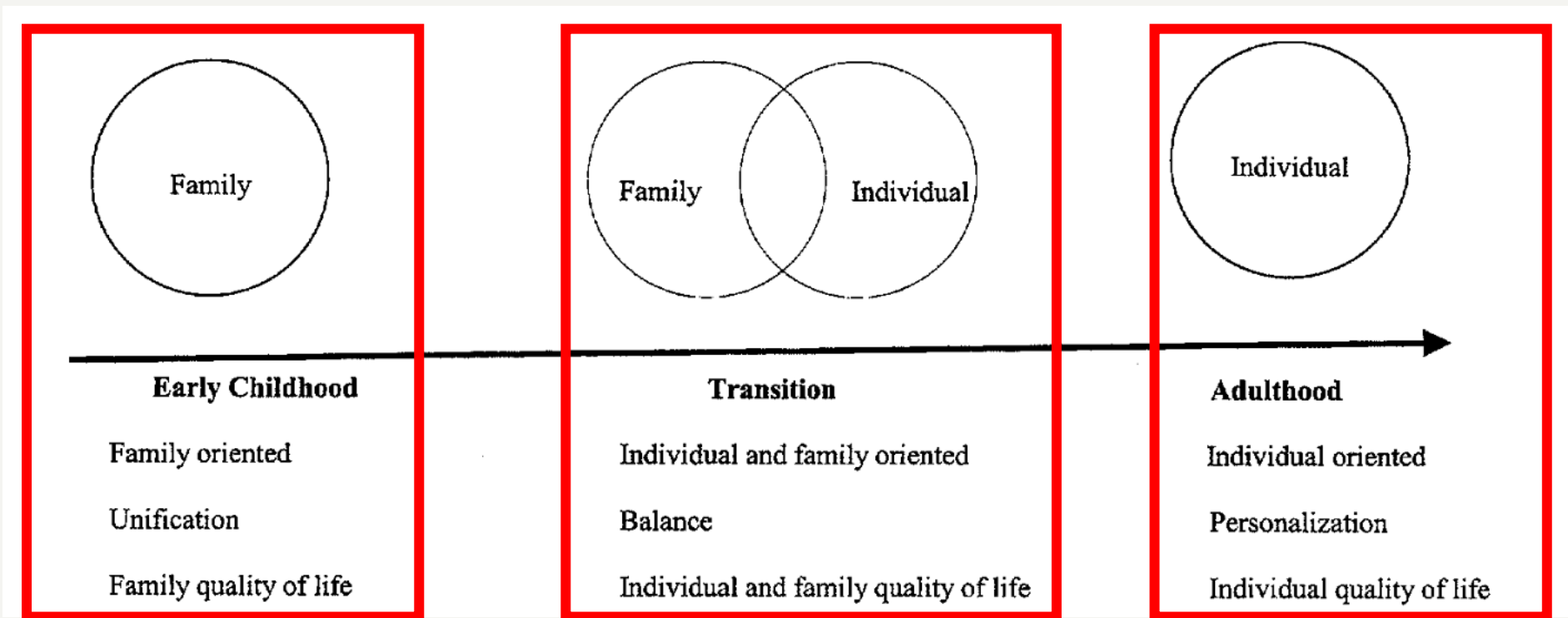


Table 1
Comparison of Person-Centered, Family-Centered, and Person–Family Interdependent Planning

Value Base	Person-Centered Planning	Family-Centered Planning	Person–Family Interdependent Planning
Choice	The person is informed. The person chooses services and supports	The family is informed. The family chooses services and supports.	The person and his/her family are informed. They choose services and supports.
Goals	The person chooses and attains his/her goals.	The family chooses and attains their goals.	The person and his/her family choose and attain their goals.
Rights	The person exercises his/her rights.	The family exercises their rights.	The person and his/her family exercise their rights.
Security	The person has economic resources.	The family has economic resources.	The person and his/her family have economic resources.
Satisfaction	The person is satisfied with his/her services. The person is satisfied with his/her life situations.	The family is satisfied with their services. The family is satisfied with their life situations.	The person and his/her family are satisfied with their services. The person and his/her family are satisfied with their life situations.

Note. Adapted from *Outcome measures for early childhood intervention services* (p. 15), by the Accreditation Council on Services for People with Disabilities, 1995, Landover, MD: The Accreditation Council.

Renzaglia et al 2003, Promoting a Lifetime of Inclusion

TABLE 1
Checklists for Promoting Normalization and Inclusion

Practice	Definition and checklist
Environmental considerations	<p>The process of identifying the factors that should be considered when designing an environment for all potential users</p> <ul style="list-style-type: none"> • Is the physical environment designed with the diverse range of potential users in mind? • Does the activity have the flexibility to accommodate a range of participants? • Are participants with disabilities being expected to fit into the activity or environment, or has the activity or environment been designed with them in mind? • Are the materials selected for the activity easily modified for accommodating the range of potential participants? • What skills would assist individuals, with or without disabilities, in successfully utilizing or participating in the environment or activity? • If instruction is needed, have strategies or contexts been selected that are flexible and can accommodate the range of learners? • Is the support structure for participation in the activity flexible and able to be adapted to the needs of individuals?
Person-centered planning	<p>The process in which the dreams and nightmares of an individual with disabilities are explored and realistic outcomes or goals for the individual are identified</p> <ul style="list-style-type: none"> • Were participants selected by the person and by his or her family? • Is the plan based on the person's dreams? • Are the services chosen to meet the goals based on the individual, regardless of whether the services already exist? • Is the plan used to create the person's IEP, ITP, or IHP?
Ecological inventory	<p>A careful and systematic approach to identifying skills that are high priority for an individual to learn to realize his or her futures plan</p> <ul style="list-style-type: none"> • What are the primary home, community, recreational, and potential work environments in which the individual spends or will spend his or her time? • Were significant persons in the individual's current residence (e.g., parents, family, housemates) assessed to determine high-priority activities and skills for instruction or needed supports for increased participation? • Were individuals in desired future residences assessed to determine high-priority activities and skills for successful placement? • Were targeted environments visited and analyzed to identify the skills that are essential for competency in each environment? • Was the individual assessed to determine which skills he or she can already perform and which he or she needs instruction in or accommodation for? • Were skills ranked in order of the most to least important for instruction? • What supports are necessary for competency in home, community, employment, and leisure and recreational settings?

Ecological Inventory and Analysis

- Per «**Ecological Inventory**» si intende un approccio attento e sistematico **all'identificazione delle competenze** più importanti da apprendere per realizzare il proprio piano per il futuro.
- Analizza ed indaga la condizioni abitativa (e quali sono i desiderata della persona stessa), quali abilità ha la persona (e quali vorrebbe avere), i supporti necessari (o desiderati), l'istruzione ecc..

Tullis et al 2019 - Incorporating Preference Assessment into Transition Planning for People with Autism Spectrum Disorder

- Come incorporare una modalità **SISTEMATICA** di assessment delle preferenze nella programmazione educativa/di vita.
- Le valutazioni sistematiche delle preferenze (S.P.A) comportano **l'osservazione diretta del comportamento** dell'allievo per determinare gli oggetti o le attività preferite e sono strumenti preziosi per determinare gli stimoli preferiti dagli allievi con ASD in una varietà di ambienti (per esempio, scuola, clinica, comunità).



Preferenza non solo di oggetti ed attività...



Ambito lavorativo: Identificare compiti o ambienti lavorativi preferiti per migliorare produttività e soddisfazione lavorativa.



Sociale e ricreativo: Determinare il livello di preferenza per le interazioni sociali o attività di gruppo per pianificare esperienze significative.



Alloggi: Valutare le preferenze per contesti abitativi e monitorare la felicità e la soddisfazione nel vivere in determinati ambienti

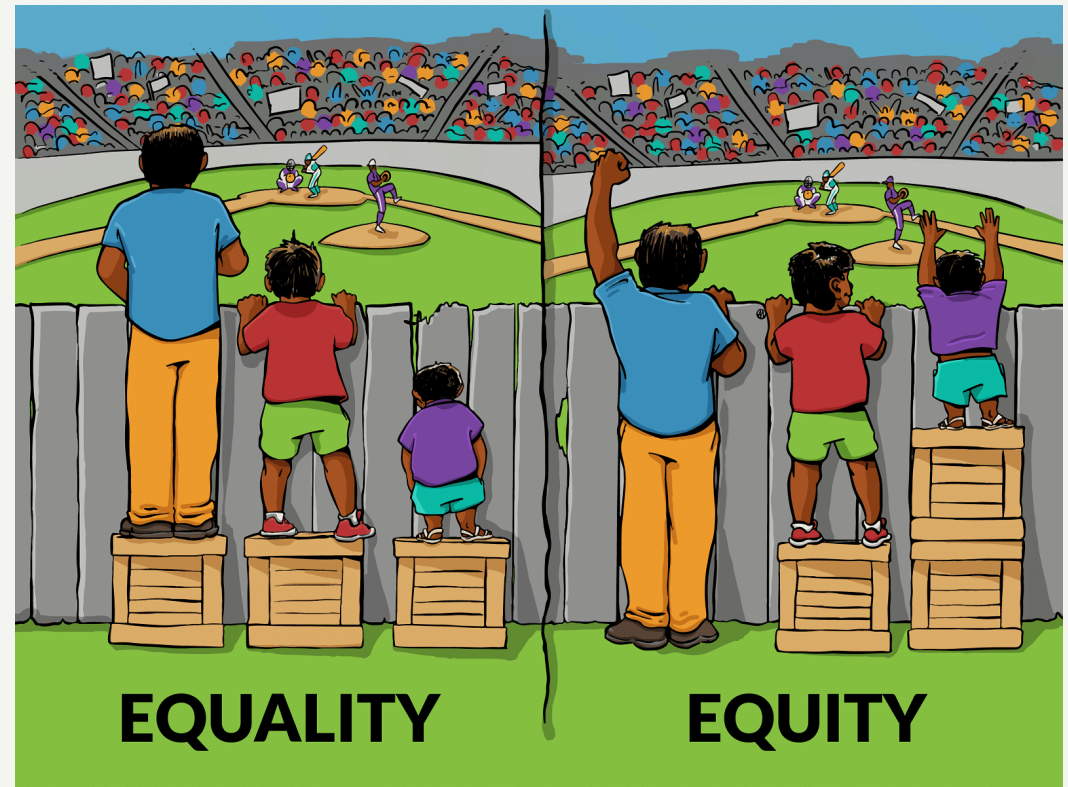
Un insieme di studi eterogenei



Valori

Vengono riportati come elemento centrale in 4 studi su 8 (Bui, Corti, Renzaglia, Kim).

I valori sono fondamentali perché costituiscono la base filosofica dell'inclusione, che è essenziale per creare ambienti equi, solidali e responsabilizzanti per le persone con ASD (Petersson-Bloom, 2022). Questi valori enfatizzano l'uguaglianza, la QoL e i diritti umani, assicurando che le persone ASD possano vivere una vita simile a quella delle persone senza ASD, con accesso alle stesse opportunità e agli stessi ambienti [Hasson et al 2024].



Limiti



L CONCETTO DI "PROGETTO DI VITA" IN ITALIANO HA UN SIGNIFICATO SPECIFICO CHE PUÒ ESSERE DIFFICILE DA TRADURRE LETTERALMENTE IN INGLESE SENZA PERDERE PARTE DEL CONTESTO CULTURALE E CONCETTUALE.



LA REVIEW È STATA SVOLTA DA UNA SOLA CON UN SUPERVISORE PER DIRIMERE I DUBBI




STUDI QUALITATIVI

Sfide Future

- Benché la natura umana sia chiaramente eterogena è necessario individuare elementi comuni per la stesura e la realizzazione dei progetti di vita.
- Niente è più pratico di una buona teoria (Lewin)
- Monitoraggio e Valutazione a lungo termine

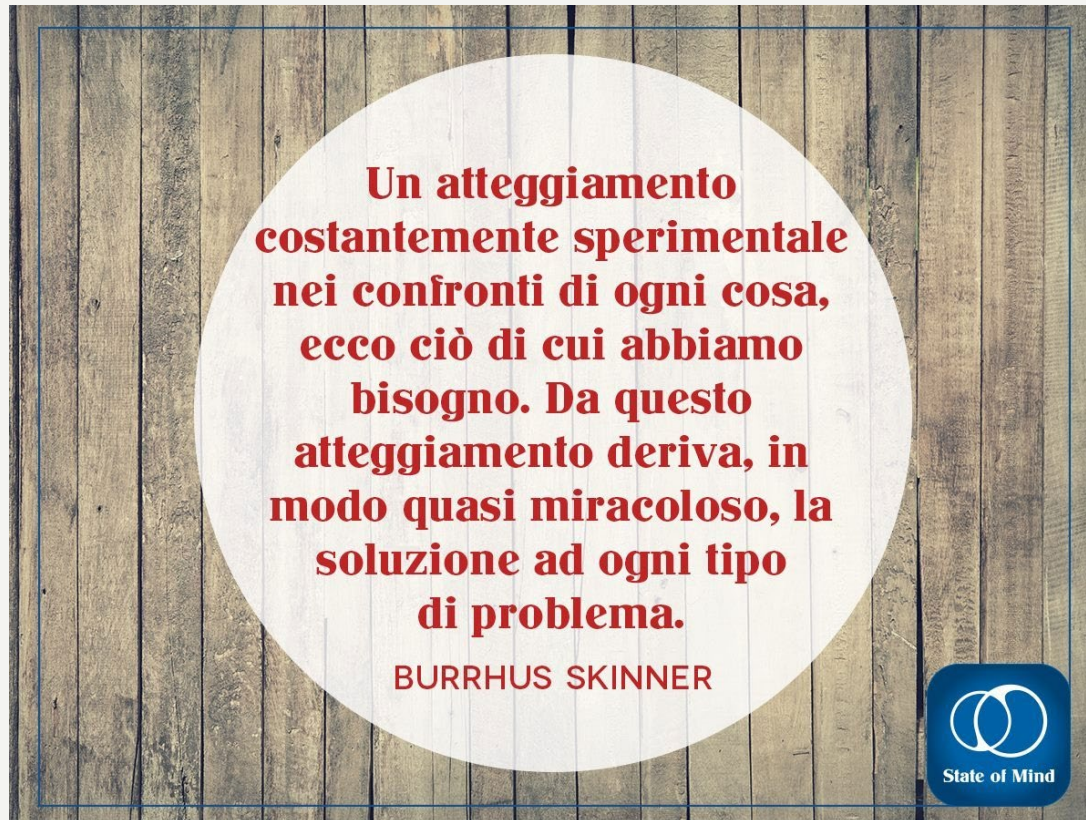
All'inizio di un lungo percorso



La voglia di perseverare è spesso la differenza tra il fallimento e il successo.

— *David Sarnoff*

Grazie per l'attenzione



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