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IPA+

Autism- training for inclusion

Module 6: Characteristic and needs in different contexts and stages of life.

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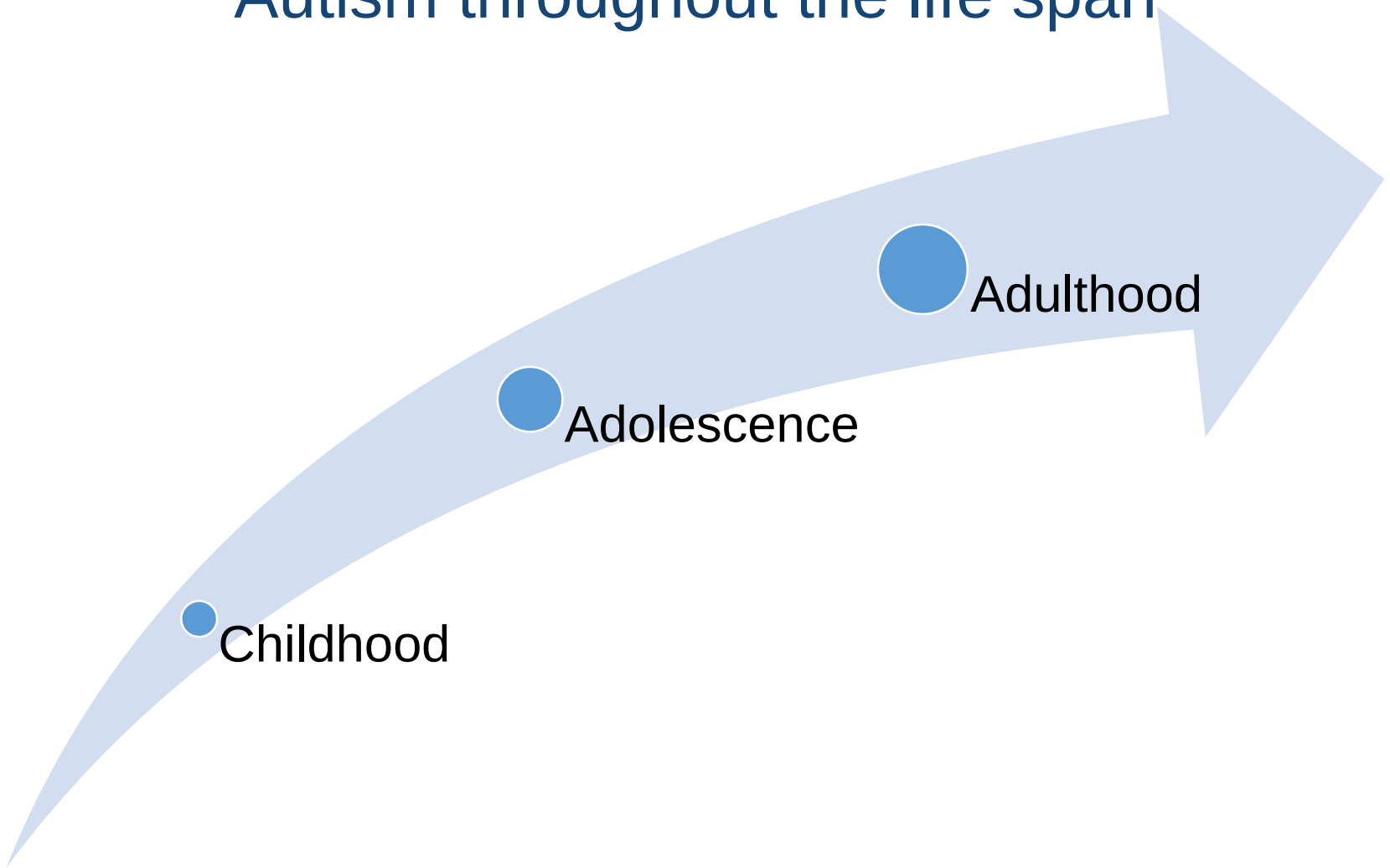
Autism throughout the life span



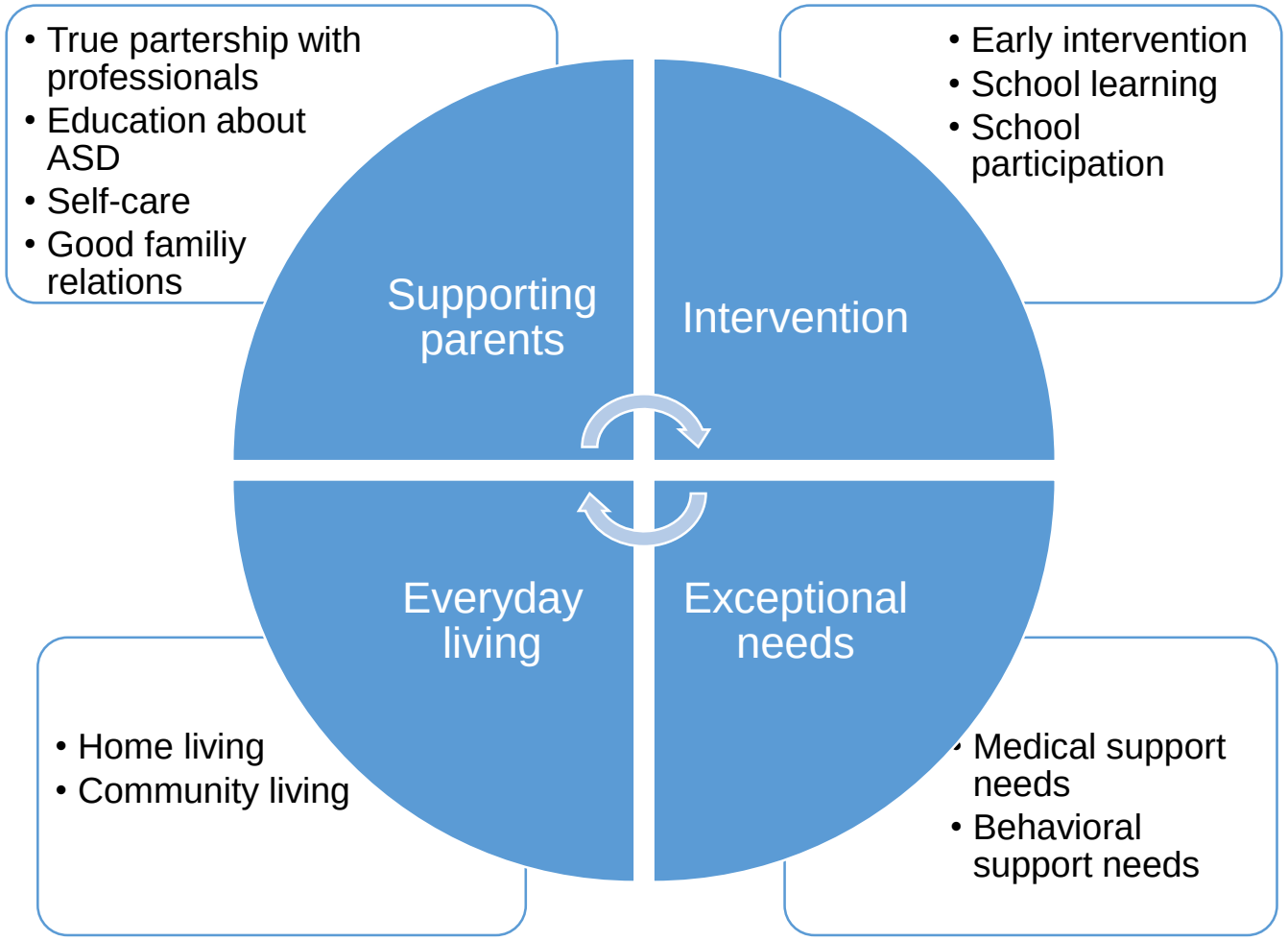
1. Presentation of autistic symptoms in a childhood

- Although parents often report autistic symptoms in the first year of life, these children have rarely been studied systematically.
- In the age between 18-36 months symptom expression appears to be stable for most children.
- In the childhood, clinicians may observe significant changes in the frequency and severity of autistic symptoms.
- Improvement of social communication skills, such as joint attention, response to name, and verbal communication, has been reported.
- Improvements in social communication tend to be greater than in a domain of repetitive behavior.

2. Support needs in a childhood are related to:

- Co-occurring behavior problems.
- Presence of intellectual disabilities.
- Parental education.
- Household income.
- Age of a children with ASD (Hartley, Schultz, 2015).

2. Support needs in a childhood



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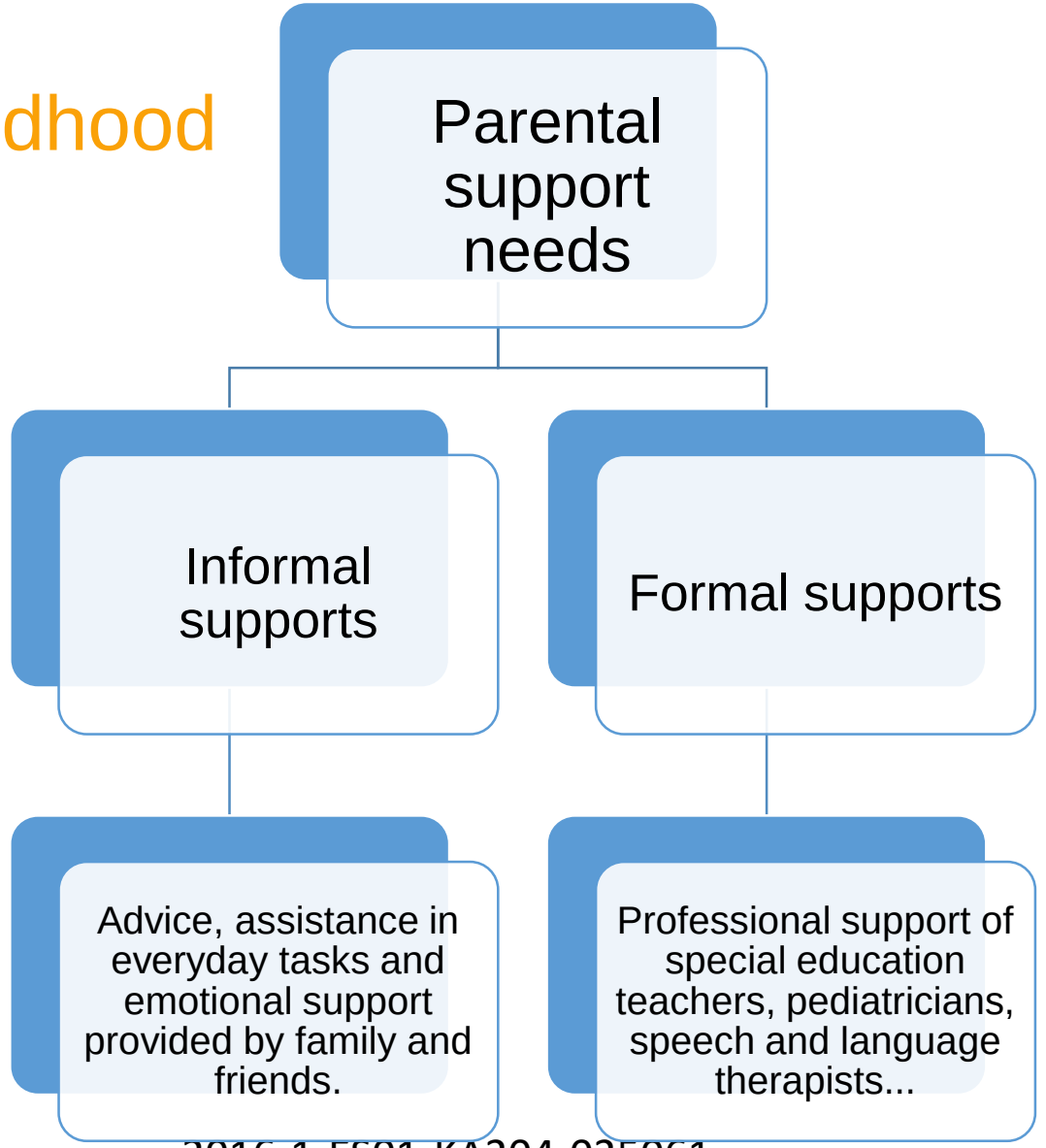
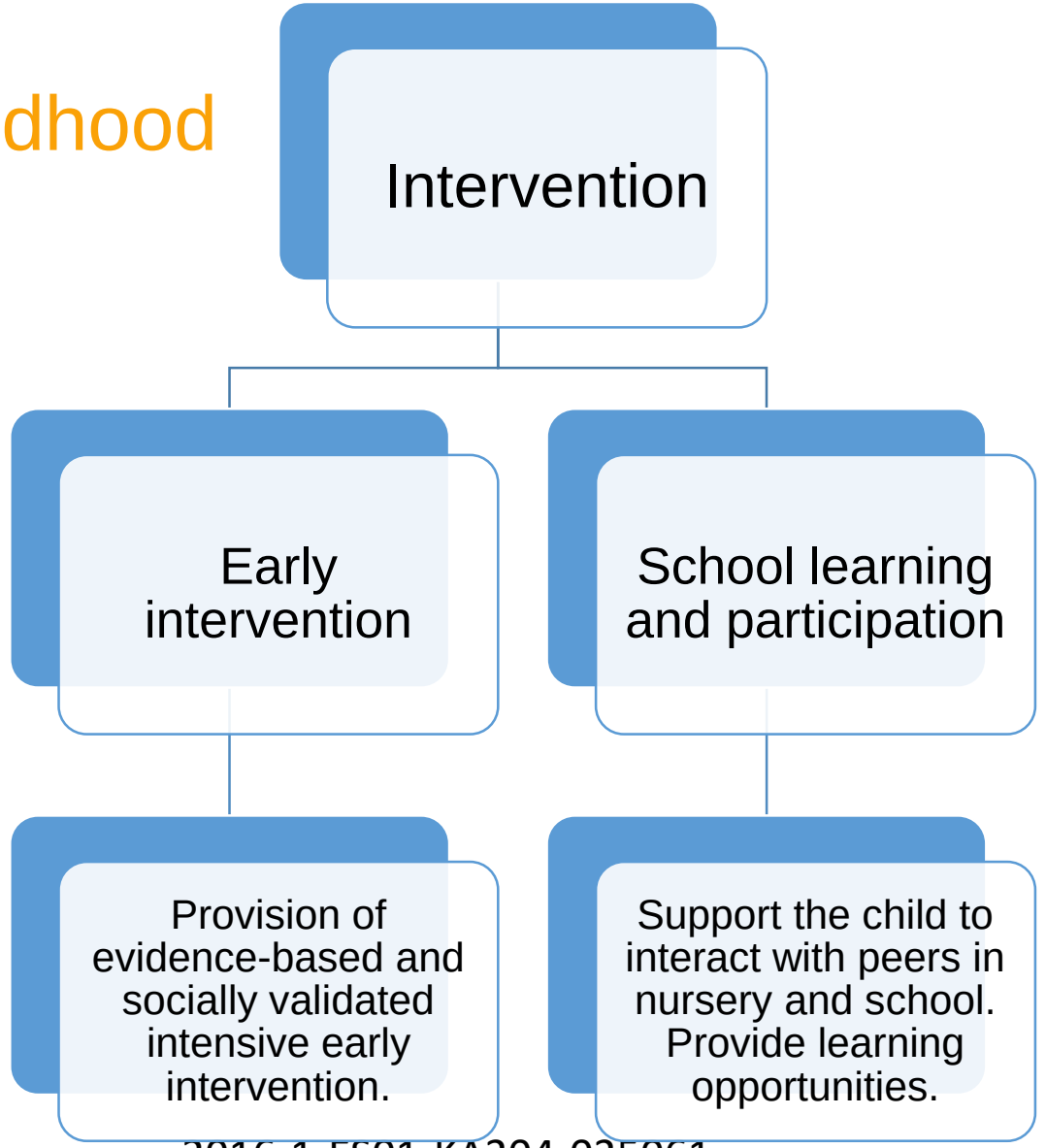
Support needs in a childhood



Support needs in a childhood



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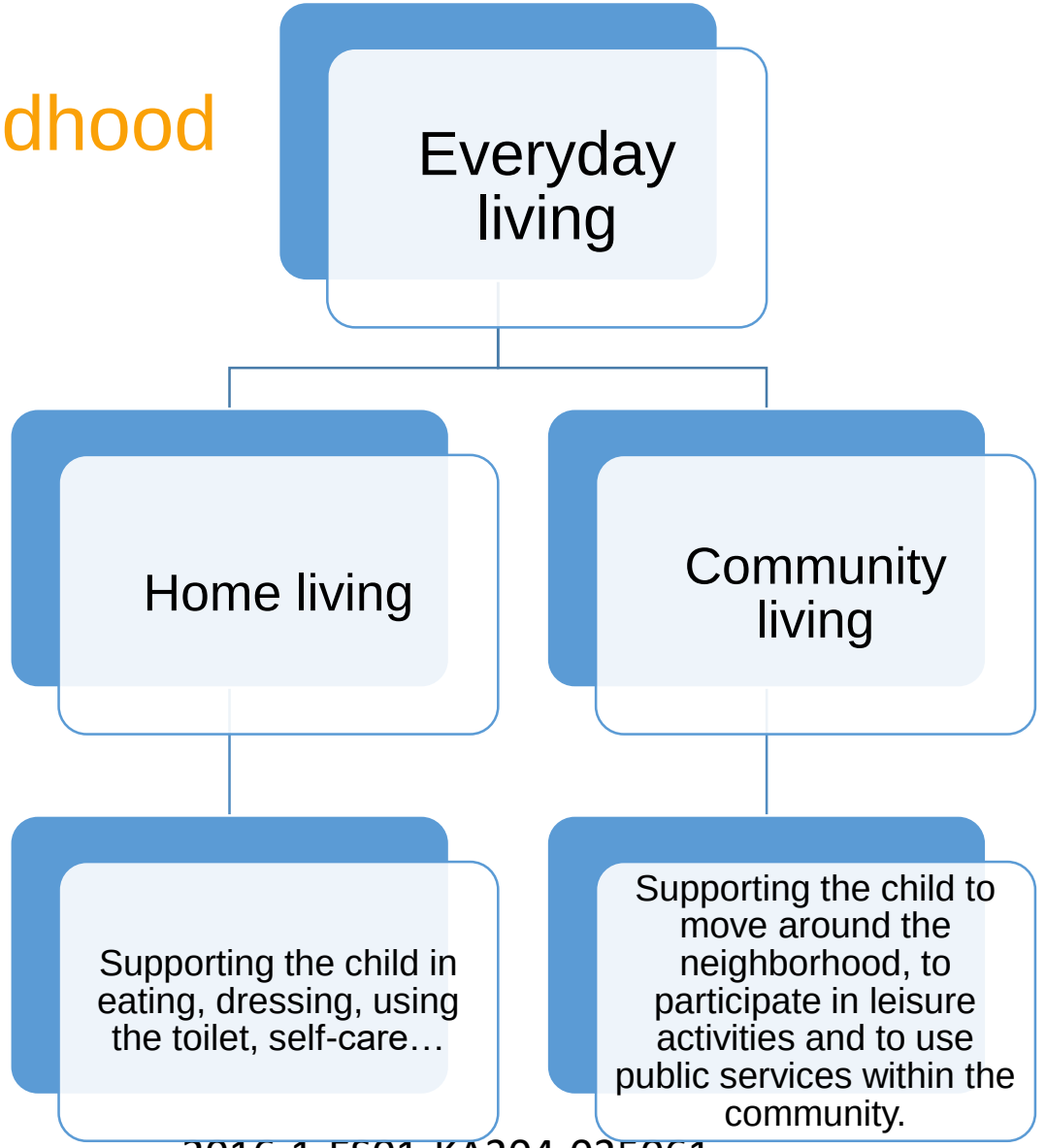
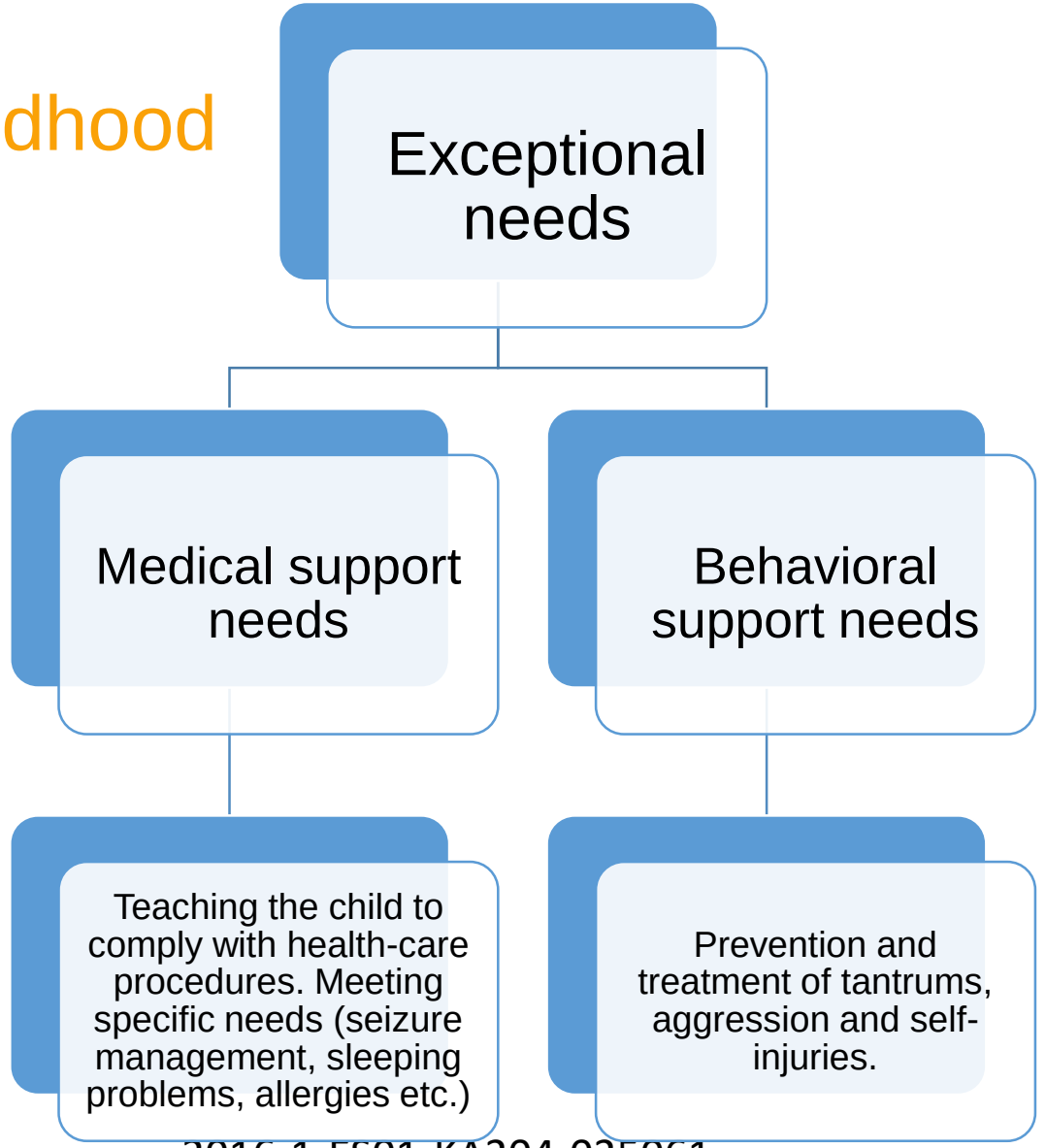
Why is early intervention important?

- The brain's ability to change (plasticity) in terms of how it responds to environmental stimuli appears to be greatest early in life.
- It allows children to experience a wider variety of learning opportunities.
- Early intervention will improve the outcome for the child.
- Intervention is likely to be less costly when it is provided earlier in the life.

Support needs in a childhood



Support needs in a childhood



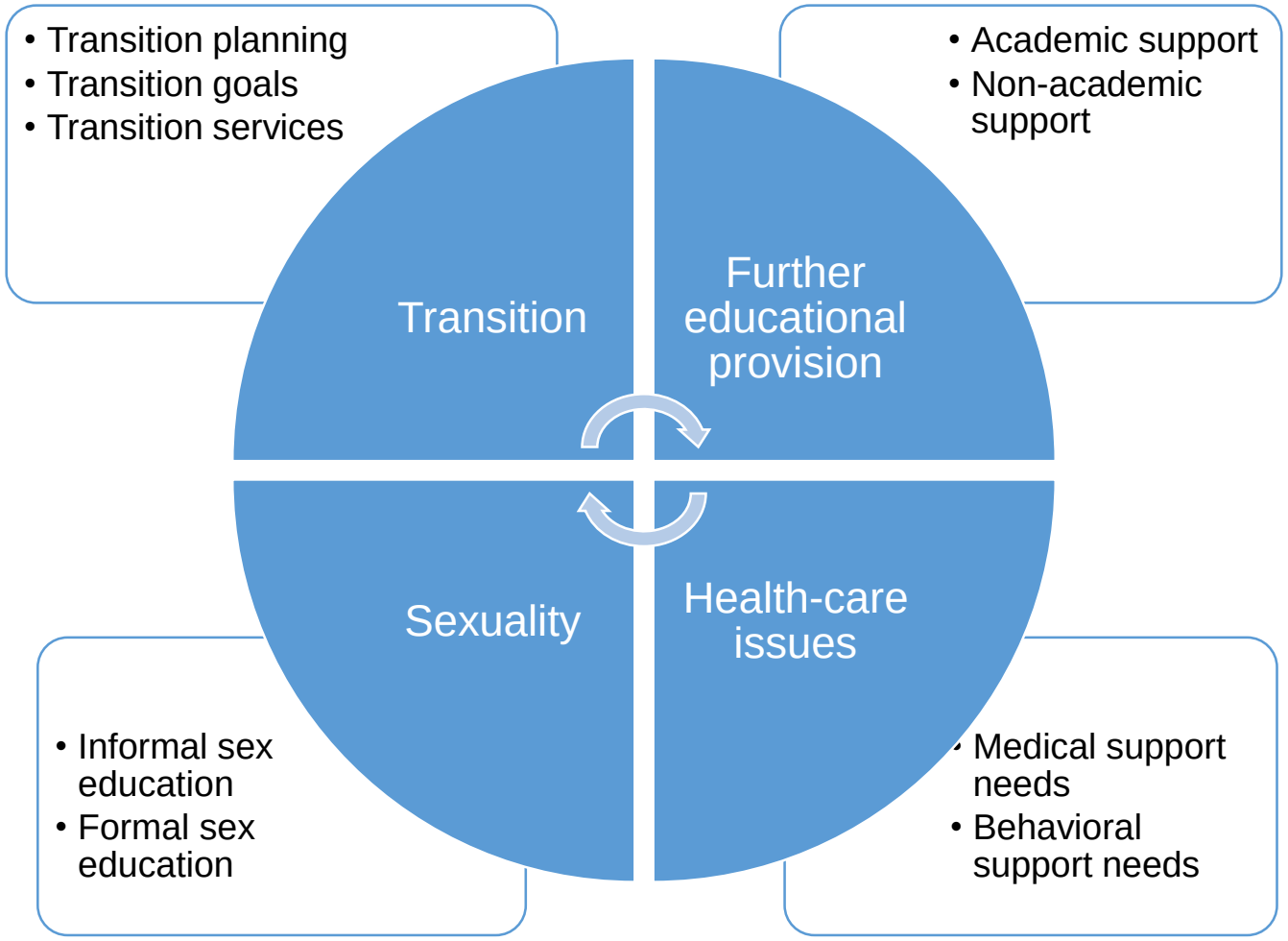
What should be done in a childhood?

- Establish both informal and formal network of support for the parents of children with ASD, according to opportunities provided in the local community.
- Include the child in an early intervention program addressing core autistic symptoms and specific difficulties.
- Enable the child to access materials, follow the curriculum and interact with peers in the nursery or school environment.
- Make a profile a support needs and a plan to meet them.

3. Presentation of autistic symptoms in adolescence

- Some individuals experience improvements that are limited to certain core features of ASD with variable timing of improvements across behaviours.
- Many individuals with ASD show increased social skill development and interest in social relationships during adolescence.
- Some adolescents with ASD may experience 1–2 year periods of aggravation of behavioural symptoms (e.g., aggression, hyperactivity, insistence on sameness).

4. Support needs in an adolescence



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Adolescence – Transition into adulthood – transition planning

- Transition plan should be written at least four years before the child is leaving the school.
- Effective plans require active participation of multidisciplinary team (special education and general education teachers, parents, adolescent with ASD, representative of support agencies etc.).
- The individual with ASD is at the center of transition process.
- Transition planning is based upon collaboration between school services and adult service agencies that provide needed support.

Adolescence – Transition into adulthood – transition goals

- What students need to learn to function as an adult?
- Goals for students with ASD should be highly individualised and focused on skills needed in current and future environment.
- It is recommended that goals for students with ASD should be related to home living, community participation, vocational and leisure activities.
- For some students with ASD transitional goals are related to post-secondary education.
- All the goals are ultimately oriented to improve autonomy and independence.

Adolescence – Transition into adulthood – services and supports needed to achieve transition goals

- Speech-language therapy
- Occupational therapy
- Assisitive technology
- Extended school year
- Vocational services
- Supported living services
- Mental health services...

Adolescence – Transition into adulthood – recommendations

- Transition plans should be based on the strengths and interests of the students.
- Transition process must include goals that are: outcome-oriented, based upon students areas of need and focused on instruction and services education, employment and other living skills.
- Ideally, this process should begin at age 14.
- Learning can be enhanced by providing instructions in natural environments.
- Educators have to know variety of teaching strategies designed to increase independence and participation.

Adolescence – Further educational provision

- When compared with the general population students with ASD have very low rates of enrolment at any post-secondary institution.
- Support has been found to significantly improve graduation rates.
- Graduates with ASD have substantially better long-term income and employment prospects compared to non-graduates with ASD.
- In some countries there is legal obligation to assist post-secondary students with ASD.

Adolescence – Further educational provision (possible strengths)

- Preserved intellectual abilities.
- Strong memory.
- Original thoughts.
- Attention to details.
- Intensive, narrow interests.
- Dedication toward studies.

Adolescence – Further educational provision (possible difficulties – personal limitations)

- Unusual social communication, atypical interests and resistance to change.
- Loneliness, anxiety and depression.
- Difficulties with time management.
- Sensory sensitivity.
- Difficulties in asking questions, participating in group work, performing presentations and understanding abstract or ambiguous concepts.
- Failure to disclose to disability services.
- Mental health issues.

Adolescence – Further educational provision (possible difficulties – societal obstacles)

- Experience of bullying.
- Sensory difficulties are rarely recognized by university authorities.
- University teachers are not aware of effective teaching strategies in working with students with ASD.
- Non-academic support is rarely provided.
- Poor information on support services.
- Complex administration procedures.
- Available support may be inappropriate and of poor quality.

Adolescence – Further educational provision (recommendations)

- Supports needed to be individualized, ubiquitous and continually monitored.
- Success is more likely when supports are consistent and frequent.
- Support services have to cover both, academic and non-academic issues.
- Mentoring is highly preferable by some (but not all) students with ASD.

Adolescence – Sexuality

- Sexual desires normally arise when one reaches puberty, and this does not differ in the case of individuals with autism.
- Sexual interests and needs are the same as in general population, but may be manifested differently due to social and communication difficulties.
- Many adolescents with autism are reported to show inappropriate sexual behavior in public due to their lack of social understanding and insufficient sexual education.
- Yet, individuals with ASD appear to receive less sexual health education than their typically developing peers.

Adolescence – Sexual relationships

- Studies demonstrate that persons with ASD display sexual interest and a wide range of sexual behaviors.
- Because individuals with ASD have deficits in the abilities required to develop and maintain interpersonal relationships, they usually have fewer friends, romantic partners, and sexual experiences than typically developing individuals (Mehzabin and Stokes, 2011).
- Person-oriented sexual activity occurs, but is usually limited to touching, holding hands and kissing. Intercourse is only rarely reported.
- A large majority of high functioning persons have sexual interests, usually heterosexual.
- Up to half of these individuals enter long-term intimate relationships and many remain undiagnosed until after these relationships have begun.

Adolescence – Sexuality – recommendations

- Informal sexual education should begin in the childhood (e.g. sense of self, circles of connection, public versus private etc.).
- Some social skills linked to sexual behavior have to be learnt during organised training (e.g. general hygiene and self-care, knowing whom is allowed to kiss or hug, knowing with whom and when one is allowed to talk about sexual matters...).
- Sexual education programs have to address the specific needs of individuals with ASD.
- Make sure that students with ASD do know how to apply information provided on sexual education classes in real life situations.

Adolescence – Medical support needs

- Adolescents with autism have the same basic healthcare needs as their typically developing peers.
- Medical comorbidity in adolescents with ASD appears to occur in numerous medical areas.
- Some individuals on the autism spectrum may not feel pain, they may find it difficult to describe what is wrong with them, or they may be extremely uncomfortable with being touched or examined.
- Majority of them are not able to independently monitor the course of the medical condition.
- Preventive services are rarely used by adolescents with ASD.

Adolescence – Behavioral support needs

- Challenging behaviors are not considered to be the core symptoms of ASD.
- Certain types of challenging behaviors (aggression, self-injurious behavior etc.) are more frequent in adolescents with autism than in their typically developing peers.
- Just like in the typical population, age is a risk factor, with higher levels of aggression occurring at younger ages, which may suggest that learning and growth may help behaviors improve.

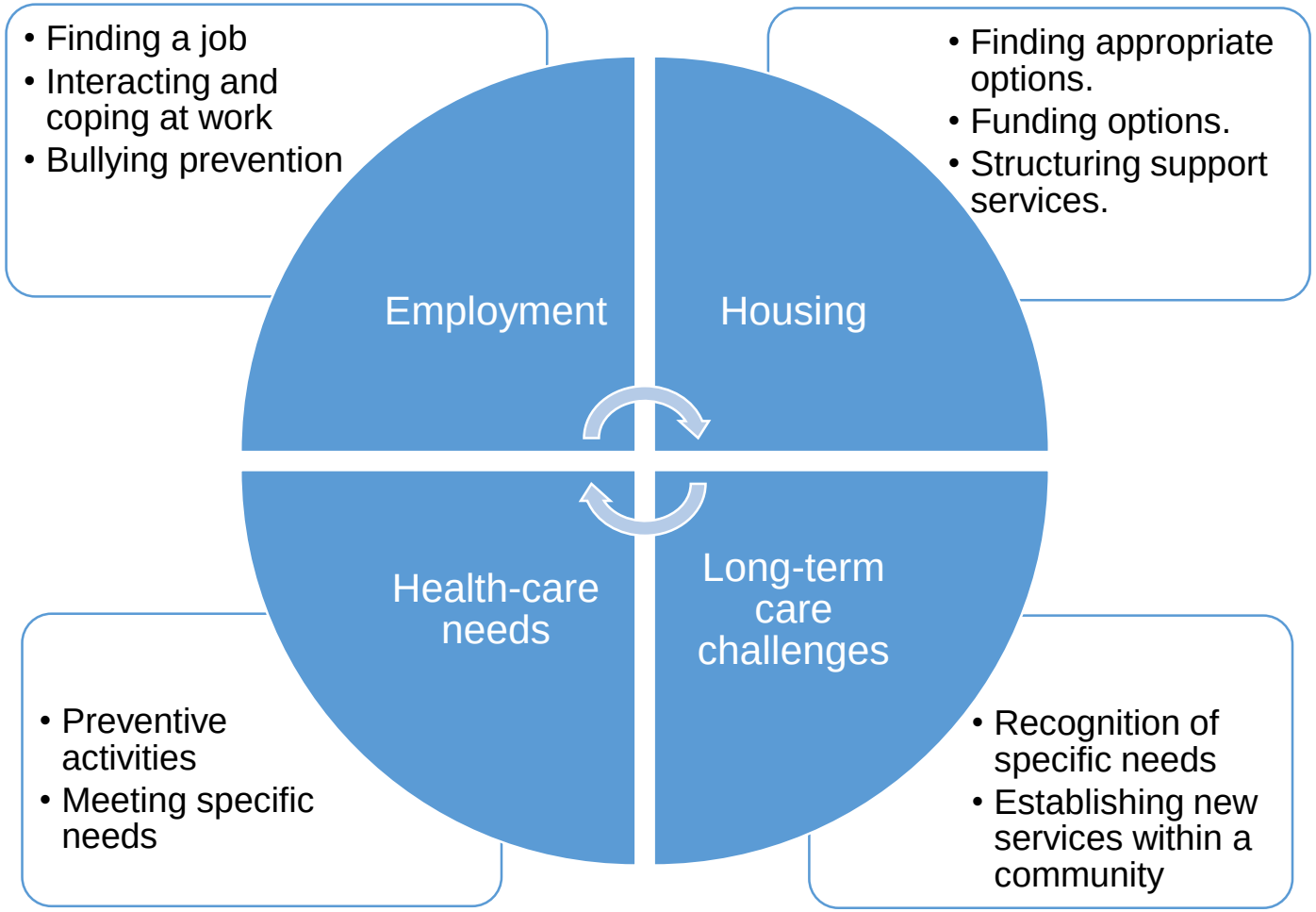
Adolescence – Medical and behavioural support needs – recommendations

- It is important to involve parents/carers in all aspects of the care as appropriate.
- Health-care professionals should be aware of specific needs of their patients with autism regarding appointments, usage of an appropriate language, preparation for medical procedures, sensory overload etc.
- Clinicians should be aware that problem behavior in ASD may be the only symptom of the underlying somatic disorder.
- Problem behaviors are often socially reinforced. That is why, they should be in the scope of behavioral interventions, rather than pharmacotherapy.
- Prevention programs are needed to address common risk factors for comorbid conditions, such as obesity, underweight, vitamin deficiency, hypo or hyperthyroidism and dyslipidemia.
- Studies suggest that exercise promotes cardiovascular and musculoskeletal fitness but has limited effects on overweight or obesity status.

5. Presentation of autistic symptoms in an adulthood

- Most individuals diagnosed in childhood continue to meet criteria for ASD in adulthood.
- Lifespan changes are highly variable across studies and individuals.
- While many individuals improve, some of them show persistent or even worsening symptoms.
- Unlike children and adolescents, adults improve more in a domain of restrictive and repetitive behavior.

6. Support needs in an adulthood



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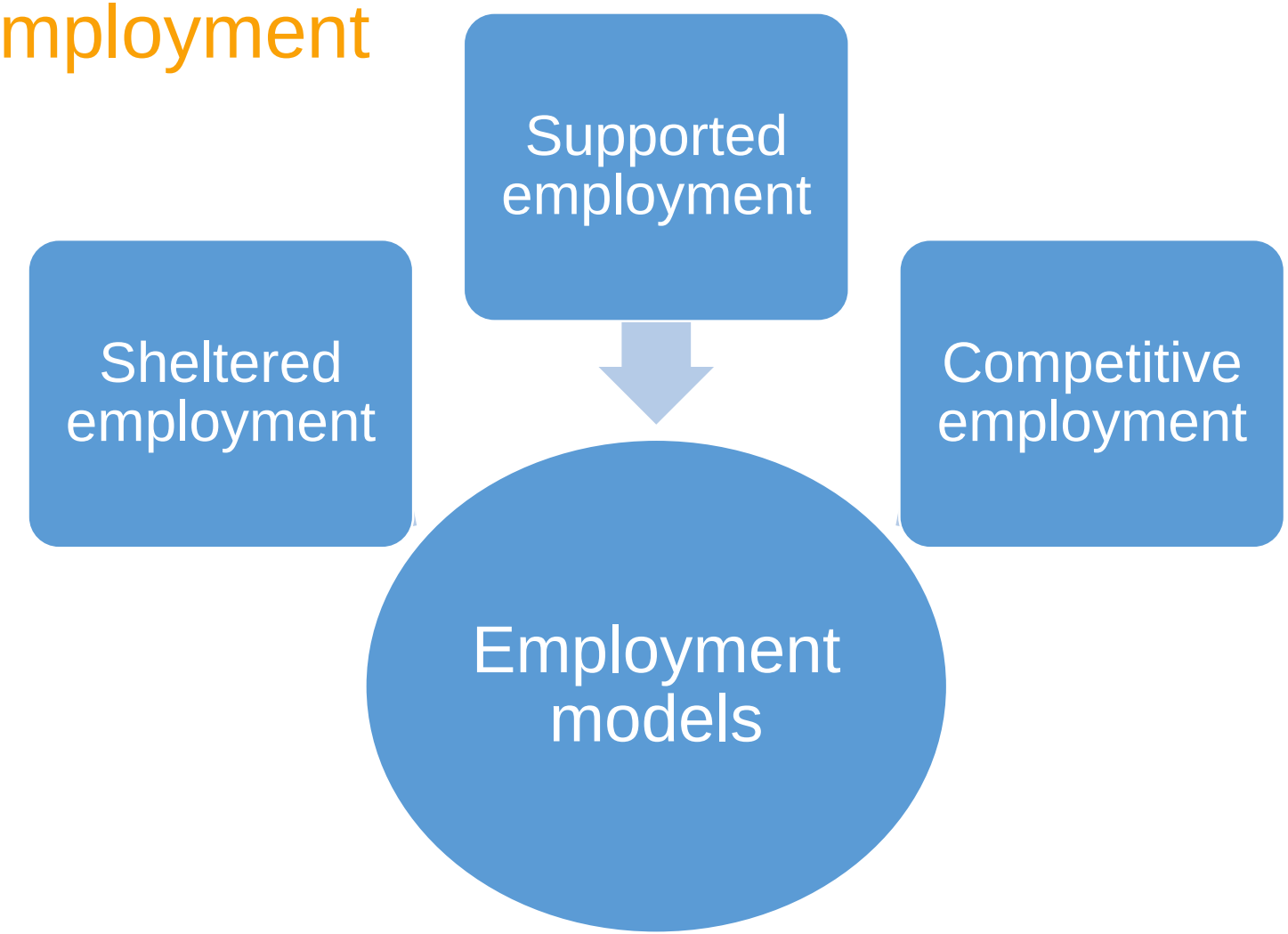
Adulthood – Employment

- Studies indicate high rates of unemployment of individuals with ASD compared to other disability groups.
- They tend to be in low paying jobs with limited working hours and in jobs that are most often well below their level of education.
- It has been suggested that one potential factor contributing to the low expectations and poor work outcomes in ASD is the emphasis on impairment and social deficits instead of strengths and expertise (Holwerda et al., 2012).
- Although individuals with ASD benefit from services to both locate and maintain employment, a high number of reports indicate that they do not receive the support services they need (Roux et al., 2015).

Adulthood – Employment



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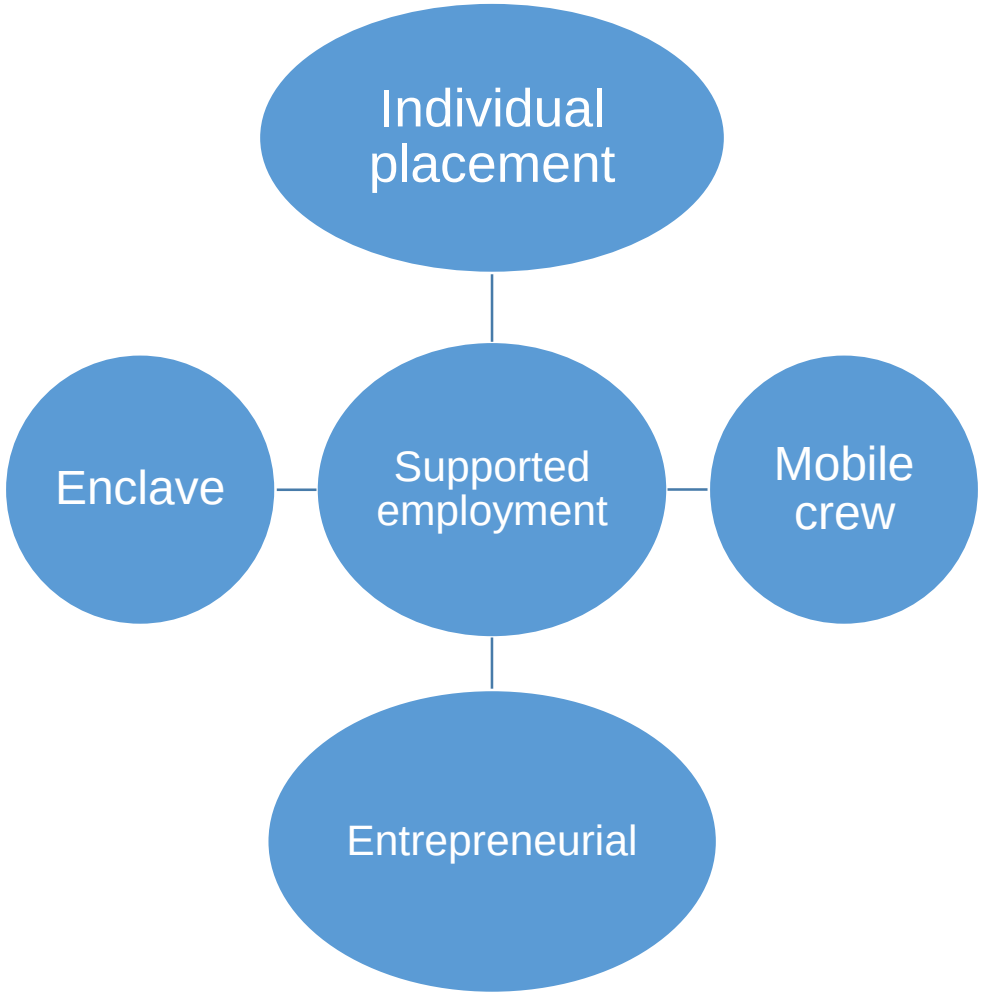
Adulthood – Sheltered employment

- Sheltered employment is also known as sheltered workshops, affirmative industries, vocational workshops, rehabilitation workshops etc.
- Jobs are guaranteed, low-wage and located in facility-like settings.
- Individuals with ASD are not integrated with typically developing employees.
- Job tasks are simple, repetitive and work productivity is lower.

Adulthood – Supported employment

- The job occurs within an integrated settings with individuals without disabilities.
- Employees with ASD are provided with natural and artificial support in order to maintain their jobs.
- Salary as well as vacation time are similar to that of individuals without disabilities holding similar jobs.

Adulthood – Supported employment



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Adulthood – Competitive employment

- Employment in an integrated environment where a person has to compete with others to obtain a position.
- No additional supports are provided.
- Wages are at a rate comparable to non-disabled workers performing the same tasks.

Adulthood – Housing options

- Adequate housing choices and supports for individuals with ASD are essential components of community living and participation.
- The number of individuals with autism living in family homes continues to increase.
- Those with a more severe degree of intellectual disability are more likely to be living in care, and those with an average IQ are more likely to be living independently.
- The move from institutional to community care is ongoing in many European countries.
- Typology of living arrangements may substantially differ across the countries.

Adulthood – Housing options

Congregated living arrangements

- Hospital-style wards
- Cluster of houses
- Residential or nursing homes

Community-based arrangements

- Group homes
- Supported living
- The individual supported living

Independent living

Adulthood – Housing options – Congregated living arrangements

- In such settings people had little choice over whom they live with; they share communal bathing facilities, dining and sitting rooms and sleeping arrangements in ward-like accommodation.
- Staff is available 24h a day, although different staff may work across the various housing units and wards.
- Most countries no longer run large developmental centers. Some countries that operate developmental centers are looking to shift people to more community-based settings and will only place a person in a developmental center on an emergency basis.
- Nursing Homes can be used to provide housing and support services to those who are more medically fragile or aged.

Adulthood – Housing options – Group homes

- Group homes – a model of shared living that accommodates up to six unrelated persons with autism (or other disabilities) in ordinary housing.
- The house is owned and operated by a provider agency that also employs and supervises the staff.
- The support staff is available day and/or night depending on residents' needs.
- Instruction focuses on independent living skills and community activities.

Adulthood – Housing options – Supported living

- Supported living offers services to individuals with autism who are able to live in a home or an apartment.
- The services, typically minimal in nature, are based on the individual's specific support needs and are provided by caregivers working under the direction of the individual.
- Persons with most intensive support needs may benefit from supported living providing that support is personalised.

Adulthood – Housing options – The individual supported living (ISL)

- ISL enables the person with a disability to live in his or her own home.
- People with autism in ISL arrangements share their homes with other people with disabilities, ONLY if this is their choice.
- ISL does not require ‘readiness’, such as a minimum level of skills, for living in a person's own home.
- Flexible and appropriate supports are available to address a person's changing needs.
- Emphasis shifts from the disability-related characteristics of the person to the processes of support.

Adulthood – Housing options – Independent living

- Living independently is an option for some individuals with high-functioning autism.
- Independent living does not imply living without support, but, unlike in other living arrangements, this support is predominantly natural.
- The road to independence may be helped by supported living schemes.

Adulthood – Health-care issues

- Adults with ASD have significantly higher rates of psychiatric comorbidity, epilepsy, infections, skin disorders and hearing impairments, compared to general population.
- High prevalence of lipid disorders among adults with ASD could be attributed to high prescription drug use in this population, possibly since early childhood.
- Individuals of all ages with ASD also exhibit higher healthcare resource utilisation such as outpatient office visits, inpatient hospitalisations, emergency room use, prescription drug use, longer length of stays and higher healthcare costs as compared to individuals without ASD.

Adulthood – Health-care issues (unmet needs)

- Research on healthcare has been almost limited to children with ASD despite the fact that people with autism will spend the majority of their lives as adults.
- Adults with autism are more likely to have unmet physical and mental health needs, less likely to receive preventive care, and more likely to end up in the emergency room (Nicolaidis et al., 2013).
- Healthcare satisfaction can be high for adults with ASD that have good family and community support.
- Healthcare providers are often uncomfortable with their level of training regarding autistic patients.

Adulthood – Health-care issues (meeting the needs by healthcare professionals)

- Adjust communication.
- Give warnings in order to facilitate transition.
- Use visual aids.
- Enlist and limit the number of caregivers.
- Use schedules for routine procedures.
- Control sensory inputs.
- Use separate and quiet waiting area etc.

Adulthood – Long-term care challenges

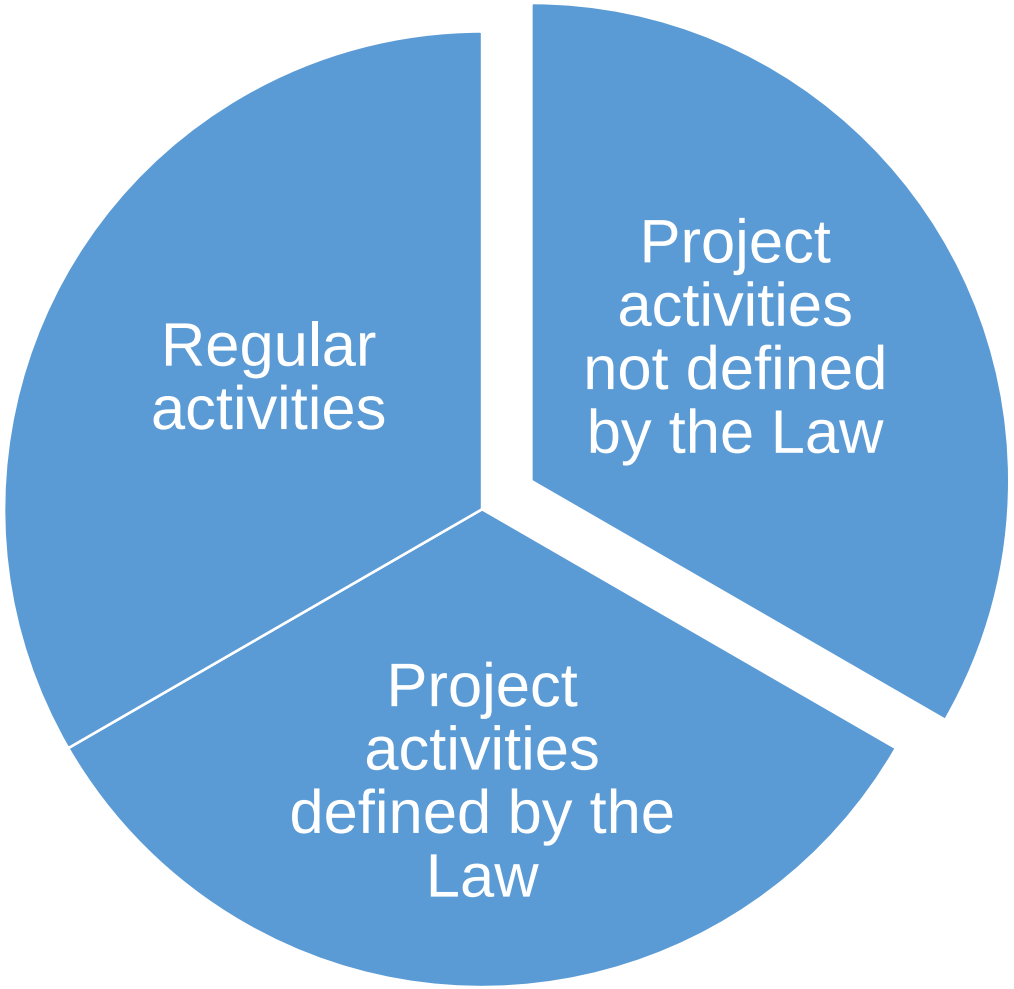
- Little is known about adults with ASD over the age of 50.
- It seems that prevalence of behavioral and psychiatric disorders steadily decreases over the time.
- Gastrointestinal disorders are more common among older than younger individuals with ASD.
- The current long-term care workforce is not trained to address the unique needs of older adults with ASD.

Adulthood – Long-term care challenges

- The high prevalence of dental, dermatological, musculoskeletal problems, and seizures encountered in older adults with ASD points to the need for careful attention to those conditions, in addition to disorders that are common in the general population as people age.
- Many of them require sedating medication to tolerate medical or dental care.
- Specific needs related to aging are yet to be determined.

7. Support services organized in Serbia

- The Law on social protection defines basic standards of social care services, application of the standards and implementation of the system for accreditation of training programs and programs for treatment and licensing of service providers.



Regular activities

Day care centers

- The purpose is to continually improve the quality of life of the beneficiaries in their own social environment through the maintenance and development of their social, psychological and physical functions and skills in order to enable them, as much as possible, to live independently.
- Available at least 8 hours per day, 5 days per week, for persons older than five y/o

Personal assistance service

- Supporting the child in mobility, personal hygiene, feeding, dressing, communication, community activities etc.
- Available for children and adolescents from seven y/o until the end of schooling.

Project activities defined by the Law

Supported living

- Support and assistance in acquiring as much independence as possible; prevention of institutialisation; inclusion in the community.
- Available for persons older than 15 y/o.

Respite care

- Development of independent life skills, inclusion in the community, empowerment of the family.
- Organized as short-term breaks for a maximum of 45 days in a calendar year, for persons aged 5-26.

Project activities not defined by the Law

Weekend program

- Used by beneficiaries of day care services as the weekend program (from Friday to Sunday) including overnight stay.

Family assistant

- Services similar to those provided by personal assistants up to four hours a day.

Links and resources

1. Chown, N., & Beavan, N. (2012). Intellectually capable but socially excluded? A review of the literature and research on students with autism in further education. *Journal of Further and Higher Education*, *36*(4), 477-493.
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6. https://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit/health
7. http://asdinfowales.co.uk/practitioner-toolkit-support-and-interventions-for-adults-with-asd
8. http://www.autism.org.uk/professionals/health-workers/guidance.aspx
9. http://www.autism-uni.org/

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