

■ Supports for Persons with Autism Spectrum Disorder (ASD)

■ Supports for persons with autism spectrum disorder (ASD) enhance accessibility and community membership opportunities for adults with autism and adolescents with autism in transition to adulthood. Education, employment, residential, social, and recreational opportunities; identification from research of successful techniques to apply to service provision including treatment and intervention research; and lifelong planning are means to achieve full inclusion and participation.

Standards for ASD services and supports present a roadmap for successful outcomes in the lives of persons with autism and their families by encouraging organizational values that focus on individualized, person-centered services for persons to achieve full inclusion and participation as desired in their communities. Services involve families, networks of resources, and education and support communities for adolescents transitioning to adulthood and adult persons with ASD.

The CARF standards in this section focus on planning for transition from school and development of lifelong supports as needed for persons with ASD, with the outcomes of employment, further education, community living, and life planning. It is hoped the standards, within the CARF values of continuous quality improvement, will provide a blueprint for community providers, local resources, and state, provincial, and federal government systems to reach and plan solutions for serving persons with ASD.

Some of the quality results (outcomes) desired by the different stakeholders of ASD services may include:

- Creating and supporting lifelong self-advocacy skills.

- Developing lifelong supports and community resources for persons and families.
- Enhancing quality of life by increasing social contacts and support communities.
- Encouraging service provider capacity building by networking with governmental, educational, business/employer, and other community resources.
- Recognizing and sharing reliable evidence-based knowledge, innovations, interventions, and therapies with proven, research-based, and peer-reviewed track records of getting results.
- Building linkages within segments of school systems and across school systems to facilitate successful transitions between placements.
- Building early linkages for transition from school to successful employment and community living supports through all life transitions.
- Providing outcomes information to schools to enhance school curriculums and employment transition planning.
- Individualized, comprehensive life planning that is continually transferred to other service providers to ensure continuity of service planning and supports.
- Persons served moving toward:
 - Optimal use of natural supports.
 - A social supports network.
 - Self-help.
 - Greater self-sufficiency.
 - Greater ability to make appropriate choices.
 - Greater control of their lives.

- Increased participation in the community.
- Employment and/or continued education.

1. The organization:

- a. Promotes community awareness of autism spectrum disorders that:
 - (1) Respects individuals with ASD.
 - (2) Supports increased community integration and participation of persons with ASD.
- b. Serves as an educational resource to its community by sharing its expertise.

Intent Statements

Through its active educational efforts the organization promotes increased community opportunities for persons with ASD. Persons with special needs are part of the community and are included without a label.

Examples

The organization promotes community awareness, understanding, and acceptance of ASD through education in its newsletter and other media publications, ability awareness celebrations, community trainings, public service announcements, and other events.

Educational efforts can help move some focus on “autistic traits” of individuals from the negative to the positive; i.e., persons who are nonverbal don’t interrupt coworkers; and also produce an inclusive-community curriculum that addresses successful transition planning from a student, parent, and community perspective.

The US Centers for Disease Control and Prevention (CDC) launched a campaign to make doctors and parents aware of the need for early diagnosis of autism. The CDC has distributed posters and checklists to doctors that describe devel-

opmental milestones for each age and also developed a distribution kit to help volunteers to reach local media outlets.

1.b. The organization shares its expertise in autism spectrum disorders in ways that are responsive to inquiries or requests. This may include participating in business advisory councils or job and provider fairs, or responding to requests for information from funders, financial planning services, medical professionals, governmental entities, local school districts and transition programs, and other community agencies or service providers who need training on practical strategies and supports for individuals with autism.

Survey Preparation Questions

1. Give some examples of how your organization:

- Promotes community awareness of ASD that:
 - Respects individuals with ASD.

- Supports increased community integration and participation of persons with ASD.

- Serves as an educational resource to the community.

2. **Based on aggregated needs and desires of persons served, the organization:**
 - a. **Identifies and networks with community resources.**
 - b. **Advocates for needed resources when these are not available.**

Intent Statements

Community resources may not be adequate to meet the needs of individuals served. The organization acts as a proactive force in the community, using information it gathers from persons and families served to promote the development of new resources and opportunities.

Organizations must be knowledgeable of community resources to fulfill this standard.

Examples

Leadership might include in its organizational planning implementing strategies to address and remove barriers to services and expand resources in the community.

The organization promotes its services to referral, educational, employer, and other significant community organizations.

A first step is to identify which agencies and resources are experienced in working with adults with autism.

Based on what is needed, the focus on building service capacity may be on increased resources in:

- Community activities
- Medical, dental, and psychological services
- Cultural activities
- Social activities
- Housing options
- Recreational activities
- Spiritual activities
- Employment/income generation activities

- Transportation
- Self-help/advocacy groups

Community resources may include the Autism Society of America, US Autism & Asperger Association, travel and leisure groups, gym memberships, socialization groups, and religious organizations.

Survey Preparation Questions

2. How does your organization, based on aggregated needs and desires of persons served:

- Identify and network with community resources?

- Advocate for needed resources when these are not available?

What are some examples of these resources?

3. **The organization:**
 - a. **Stays current with peer-reviewed research and validated innovations for treatment, training, and program design.**
 - b. **Shares information regarding these in an understandable manner with persons and families served.**
 - c. **Utilizes its own outcomes and data systems to analyze its results in service delivery.**

- d. **Strategically positions its service and business design based on:**
 - (1) **Autism research findings, as available.**
 - (2) **Service outcomes information.**
- e. **Promotes interagency collaboration, including information sharing on autism services and designs.**

- Shares information regarding these in an understandable manner with persons and families served.

Intent Statements

Organizations that exist to make a difference in the lives of persons with autism collect and share information on service results.

- Utilizes your outcomes and data systems to analyze its results in service delivery.

Examples

The organization is actively involved in learning about current trends in autism and services to persons with autism. This may be demonstrated by conference and training participation, accreditation, outcomes management systems, and annual reports of effectiveness and efficiency.

A role the organization may play is helping families sift through the tremendous volume of research and treatments in the area of autism that do not encompass best practice and can be misleading to persons and families affected by the diagnosis.

- Strategically positions its service and business design based on:

- Autism research findings, as available.

- Service outcomes information.

Survey Preparation Questions

3. Explain how your organization:

- Stays current with peer-reviewed research and validated innovations for treatment, training, and program design.

- Promotes interagency collaboration, including information sharing on autism services and designs.

4. **Service strategies are based on awareness of one or more of the following:**
- Research that has indicated successful techniques.**
 - Evidence-based practices.**
 - Field recognition from professional or advocacy organizations.**

Describe how your organization uses the above as the basis for its service strategies.

Intent Statements

Services are designed around current best practice, and results are continually examined to revise services to become even more effective in achieving results desired.

Examples

Research has documented the importance of programming for generalization with persons who have an autism diagnosis (Powers, 1992). Unless this issue is specifically addressed, persons with autism are likely to fail to generalize skills and what they have learned across other settings, environments, people, and materials. Service providers do “fix” the individual, but rather learn how to change the way they are supporting the individual with autism to better achieve desired outcomes.

Survey Preparation Questions

4. Are your program’s service strategies based on awareness of:
- Research that has indicated successful techniques?

Yes No
 - Evidence-based practices?

Yes No
 - Field recognition from professional or advocacy organizations?

Yes No

Did you answer *yes* for at least one of the above choices?

Yes No

5. **The program identifies the competencies required of personnel providing services, including:**
- Meeting, as applicable, licensing, credentialing, and certification requirements.**
 - Meeting identified educational requirements.**
 - Demonstrating competency related to:**
 - (1) **The needs of persons with ASD.**
 - (2) **The requirements of the job.**
 - (3) **Training specific to the service provided.**

Intent Statements

ASD is by its very nature a spectrum. All too often the individuals with the greatest needs are not adequately or realistically addressed in supports and services. The organization is expected to identify the extent of its services and the required expertise of personnel to support the served population.

Examples

There are adequate numbers of qualified personnel to achieve successful outcomes for persons served.

Survey Preparation Questions

5. Where do you identify the competencies required of personnel providing services in the following areas:

- Meeting, as applicable, licensing, credentialing, certification, and educational requirements.

- Demonstrating competency related to.

- The needs of persons with ASD.

- The requirements of the job.

- Training specific to the service provided.

If applicable, what are identified credentialing requirements?

If applicable, what are identified educational requirements?

How do you determine that personnel demonstrate these competencies?

6. Based upon individual needs and desires, the services facilitate supports for persons and/or families served with community resources that offer:
- a. A variety of life experiences.
 - b. Opportunities for community access.
 - c. Opportunities for community inclusion.

Intent Statements

The persons served have opportunities to develop or increase social contacts, new supports, and community networks.

Examples

The organization provides individualized services and it supports community membership and inclusion as goals, but the extent is determined by the desires of each individual person.

Survey Preparation Questions

6. What is your process to ensure that, based upon individual needs and desires, services facilitate supports for persons and/or families served with community resources that offer:

- A variety of life experiences.

- Opportunities for community access.

- Opportunities for community inclusion.

List some examples.

7. The services provide information about or referrals to networks of community supports to persons served, as desired, in the areas of:
- a. Educational development.
 - b. Living skills development.
 - c. Interpersonal relations.
 - d. Recreation and leisure time opportunities.
 - e. Vocational development, employment, or career advancement.
 - f. Access to generic community social resources.

Intent Statements

Through providing information or referrals to supports the organization facilitates growth and development in the personal lives of persons served. Services enhance opportunities for independent and productive living.

Examples

Information might be provided in different ways, such as using an existing community resource directory or a compilation by United Way. This information could give persons access to supports as desired to enhance independent living skills, money management skills, communication skills, social interactions, exercise, community employment opportunities,

house keeping activities, hygiene, food shopping, meal preparation, reduction of maladaptive behaviors, and use of community resources, e.g., library or gym.

7.f. Generic community resources are resources in the community that are used by the general population without disabilities.

Survey Preparation Questions

7. Do your services provide information about or referrals to community supports to persons served, as desired, in the areas of:
- Educational development?
 - Information
 - Referral
 - Both
 - Living skills development?
 - Information
 - Referral
 - Both
 - Interpersonal relations?
 - Information
 - Referral
 - Both
 - Recreation and leisure time opportunities?
 - Information
 - Referral
 - Both
 - Vocational development, employment, or career advancement?
 - Information
 - Referral
 - Both

- Access to generic community social resources?

- Information
- Referral
- Both

If applicable, give some examples of how you provide information to persons served about the areas listed above.

If applicable, describe your referral process.

8. The services assist persons and/or families served in enhancing their quality of life by providing opportunities to develop and/or increase as desired:
 - a. Social networks.
 - b. Personal relationships.
 - c. Community supports.
 - d. Supports from peer mentors, alumni from the program, or self-advocates with real life experiences.

Intent Statements

The persons and/or families served are included in their communities to the degree they desire.

Examples

Opportunities are based on the unique learning style of each individual and the need for individualized supports. Peer mentors add the dimension of persons with ASD who understand the personal needs of a person with ASD. Families are provided with opportunities to meet with

other families who have participated or are participating in the program. Families often benefit from parent-to-parent support that can be accessed from a family support network component.

Based on the level and age of the person served, there could be great variability in availability and involvement of the family or in the desire of the person served to have the family involved.

Survey Preparation Questions

8. Give some examples of opportunities that your services have provided to assist persons and/or families served in enhancing their quality of life by developing:

- Social networks.

- Personal relationships.

- Community supports.

- Supports from peer mentors, alumni from the program, or self-advocates with real life experiences.

9. Self-advocacy support services are individualized to each person served and his/her family.

Intent Statements

Support is given to persons and families served for development of their advocacy skills.

Examples

Support for advocacy activities may be provided within the organization, through support for participation in activities such as consumer councils, or support for self-facilitation of a person's individual planning meeting; or in the community, through support for participation in activities sponsored by advocacy groups; or support in self-advocacy to access benefits, services, etc. These examples of self-direction are not the only means by which support for advocacy may be provided.

An important first step is ensuring that persons served feel safe in their environment before they explore opportunities to enhance their advocacy skills. There also must be a strong emphasis on communication, including teaching how to communicate, providing tools with which to communicate, and making sure that communication systems are part of every plan. Self-advocacy does little without the ability to communicate. Likewise, due to prevalent dysfunction in choice-making being one of the characteristics of autism, choice-making may have to be taught through supports and experience. For some persons who are not capable of participating themselves, this might include significant others, i.e., family, friends, or respite providers. This might include the concept of creating a support circle, as many families are isolated and don't have anyone other than themselves to support the individual with autism.

Survey Preparation Questions

- 9.** What is your process to ensure that self-advocacy support services are individualized for each person served and his/her family?

Give some examples of individualized self-advocacy support services or activities you have provided to persons or families served:

- 10. As desired, persons served have opportunities to enhance their quality of life through:**
- a. Self-advocacy skills training and support systems.
 - b. Maintaining or strengthening social contacts.
 - c. Developing social contacts.
 - d. Creating a support circle, including supporting the person to designate an advocate.
 - e. Developing new skills and supports on an ongoing basis, including self-determination.

Intent Statements

Quality of life is specific to and defined by each person and/or family served. Skills and supports to enhance quality of life will be determined and their effectiveness reported by persons and families served. Accessibility to forums of self-determination and decision making is key to meeting the needs of persons with ASD.

Examples

10.a. Examples of self-advocacy may include attending and participating in individual program plan meetings, goal development, employment opportunities, participating in community meetings, attending human rights conferences and trainings, membership on human rights committees and other organizational boards, participating in group leisure activities and travel, participating in political events and voting, and participating in safety committees. Alternative methods for self-advocacy, e.g., non-verbal, may be used. Depending on the persons served, efforts may focus on very basic skills such as communication of basic wants and needs.

10.d. The person may designate an advocate to act on his/her behalf from significant others such as family members, friends, or respite providers.

Survey Preparation Questions

10. How are persons served given, as desired, opportunities to enhance their quality of life through:

- Self-advocacy skills training and support systems?

- Maintaining or strengthening social contacts?

- Developing social contacts?

- Creating a support circle, including supporting the person to designate an advocate?

- Developing new skills and supports on an ongoing basis, including self-determination?

11. The organization assists families served, as desired, to:

- a. Develop a personal circle of advocates.
- b. Have opportunities for parent-parent supports and networking.

Intent Statements

To promote community accessibility and quality services, organizations assist individuals and families to establish partnerships, networks, and coordination with other agencies.

Examples

Examples include developing natural supports at an individual's place of employment, significant relationships with staff, clergy, other family members, and members of local chapters of advocacy organizations; e.g., Autism Society of America, Association of Retarded Citizens, and US Autism & Asperger

Association, Inc. The organization may link the family to an appropriate community agency that can assist with this.

Survey Preparation Questions

11. How does your organization assist families served, as desired, to:

- Develop a personal circle of advocates?

- Have opportunities for parent-parent supports and networking?

12. Persons and/or families served are given opportunities to enhance their advocacy skills through participating in systems advocacy activities.

Intent Statements

Systems advocacy promotes effective service delivery systems for the individual and his/her family.

Examples

Examples include membership of persons served or family members on a board of directors of a human service agency, state agencies, foundations, chambers of commerce, unions, and business advisory councils.

Survey Preparation Questions

12. Give some examples of opportunities you have provided to persons and/or families served to enhance their advocacy skills through participating in systems advocacy activities.

13. The organization provides to the person served and family information on life stages through:

- a. Ongoing communication.
- b. A family support network component.
- c. Opportunities for support services.
- d. Referral sources for specialized and generic care and support needs.

Intent Statements

The organization provides information to the person and family served to facilitate timely planning for transitions related to changes and transitions in life stages.

Examples

Options and choices are provided for creating individual services that support successful aging. Participants are unlikely to have static needs across the lifespan, and extra supports and assistance during major milestones are especially needed.

Examples include state agency personnel who provide information and training on community resources and benefits planning; funding and program opportunities; foundation grants; referrals to insurance agencies, financial and estate planners, and allied health professional resources in the areas of speech, behavioral, occupational, and physical therapies; and autism-specific resources.

Survey Preparation Questions

13. How does your organization provide to the person and family served information on life stages through:

- Ongoing communication?

- A family support network component?

Give some examples of information on life stages your organization has provided related to:

- Opportunities for support services.

- Referral sources for specialized and generic care and support needs.

14. Strategies for reasonable accommodations include, as needed, the use of assistive technology or adaptations in:

- a. Communications.
- b. Environmental control.
- c. Mobility, orientation, or destination training.
- d. Education and training.
- e. Activities of daily living.

- f. Employment.
- g. Recreation.
- h. Sensory needs.
- i. Transportation.
- j. Other needs as defined by the person served.

Intent Statements

Assistive technology and other reasonable accommodations enable persons served to have increased access to or participation in life, employment, education, and/or inclusion in the community.

Examples

Examples include communication devices, communication “books” and booklets, facilitative communication, and sign language; sensory sensitivity accommodations; handheld devices and computers; travel training; cellular phone communication; independent living skills; supported and independent employment including micro-enterprise and part time work; gym and sports activities; and public and other alternative opportunities for travel.

Survey Preparation Questions

14. What is your process to ensure that reasonable accommodations, including the use of assistive technology and adaptations, are made as needed?

Give some examples of the use of assistive technology or adaptations you have provided related to:

■ Communications.

■ Environmental control.

■ Mobility, orientation, or destination training.

■ Education and training.

■ Activities of daily living.

■ Employment.

■ Recreation.

■ Sensory needs.

■ Transportation.

■ Other needs as defined by the person served.

15. If the person served desires, assistance is provided to the person to develop and maintain a personal scrapbook that captures:

- a. Significant events and milestones for the person.
- b. The person's accomplishments.
- c. Successful communication systems for the person.
- d. Other information, as appropriate to the person.

Intent Statements

This personal document would grow on an ongoing basis so that the compilation can be shared by the person with people who come into the person's life to help them know the person and what is important to him/her. It may be an aid in helping some persons with ASD to experience greater self-realization or self-acceptance.

Examples

The scrapbook is consolidated across all disciplines serving the person and includes the individual, advocates, and family, and things such as photos, videos, and prompts.

Survey Preparation Questions

- 15.** Is assistance provided to each person served, as desired, to develop and maintain a personal scrapbook?

Yes No

If *yes*, does each scrapbook capture:

- Significant events and milestones for the person?

Yes No

- The persons accomplishments?

Yes No

- Successful communication systems for the person?

Yes No

- Other information, as appropriate to the person?

Yes No

Describe how you assist persons served to decide if they want a personal scrapbook.

How do you ensure that the person's scrapbook is kept current and contains all of the appropriate information?

Please give some examples of other types of information that has been included in the scrapbooks of persons served.

Does the person make the decision about whom to share the scrapbook with?

Yes No

Can you identify a person who would share his or her scrapbook with the surveyor?

Yes No

If *yes*, please be prepared to have this person available during the survey.

- 16. Historical information about each person served is maintained and shared with other providers or educators, as appropriate, that includes:**

- a. Strengths, abilities, and successes.
- b. Relevant medical information, as available.
- c. Psychological information, as available.
- d. Social information.
- e. Successful strategies to support learning, behavior, communication, and building social networks.
- f. Situations that should be directed differently.
- g. Key professionals involved in providing services to the individual.

Intent Statements

By sharing the successful experiences, service approaches, and desires of the person served, consistency and greater continuity of services during transitions in the person's life is possible.

Examples

Historical information about each person served includes individual education plans, individual service plans, individual program plans, consultations, and allied health service reports.

Documentation may be collected regularly through behavioral data collection and presentation at individual program plan meetings with the individual and other significant stakeholders.

Documentation should include the “must haves” in the person’s life, e.g., low lighting, soft music, baseball cap.

Survey Preparation Questions

16. Is historical information about each person served maintained and shared with other providers and educators as appropriate?

Yes No

If *yes*, does the historical information include:

■ Strengths, abilities, and successes?

Yes No

■ Relevant medical information, as available?

Yes No

■ Psychological information, as available?

Yes No

■ Social information?

Yes No

■ Successful strategies to support learning, behavior, communication, and building social networks?

Yes No

■ Situations that should be directed differently?

Yes No

■ Key professionals involved in providing services to the individual?

Yes No

What is your process to ensure that historical information is updated and maintained on an ongoing basis?

What is your process to ensure that historical information about the person served is shared with other providers or educators as appropriate?

17. Employment service organizations create successful employment results based on:

- a. Outreach to collaborate with educational resources to enhance education curriculums that address employment or future educational goals upon leaving school.
- b. Social skills training to enhance success in employment settings.
- c. Utilization of community resources to meet individual needs.
- d. Educational information for the employer about the individual, such as understanding about communication mode, environmental requirements, and processing patterns.

Intent Statements

Curriculum design, training approaches, and educational information are continually improved to create successful individual employment outcomes.

Examples

17.a. Curriculums apply to how prepared for employment a person is as they leave school; i.e., can they carry a wallet? Do they have a social security card? Do they have all the I-9 papers required to be employed? Do they have some part-time work experience or at least some exposure to a work environment?

Other examples include:

- The organization provides an intense, rich array of developmental experiences in vocational and employment areas that contain high expectations

and challenges for each individual, allowing for dignified risk taking and respecting the individual's competencies and preferences.

- The organization assists individuals in developing, maintaining, and obtaining more work skills for increased independence.
- The organization provides the person served with a sampling of community job opportunities.
- The organization maximizes the earnings of each individual in the program.
- The organization assists the person served in acquiring social and communication competencies to enable him/her to function more effectively in job settings and other environments?
- The organization works toward reducing individual dependency on staff through appropriate job matches and natural workplace supports.

Training components for community resource personnel are conducted and may include:

- Introduction to autism
This is designed to provide an understanding of ASD and includes a review of the research and knowledge of developmental disabilities and autism, the distortions that continue to permeate current understanding, and the resultant impact upon persons labeled autistic. The training teaches that autism has the basic primary impairments of learning deficits, problems with language communication, perception, and sensory experience that have a profound impact upon cognitive, emotional, and social development. This may result in secondary challenges, especially behavioral.

■ Learning style

This is a more detailed review of specific learning issues encountered by persons served. The impact of specific high and low skill areas upon the learning process is reviewed and discussed with persons served with the development of a detailed profile of their needs that is then paired with recommendations for improved instructional strategies.

■ Analyzing the communicative functions of behavior

This provides an in-depth examination of the processes of contextual, communicative, and functional analyses of problematic behavior. Misconceptions regarding communication, behavior, and the utilization of applied behavioral analysis and a consideration of major research on these topics may be reviewed and discussed. Personnel learn how to interpret and respond to the maladaptive behaviors of persons served by understanding the possible messages. Then they can learn to respond to these messages, design modifications in the environment, modify or discard inappropriate requirements, and teach the communication skills to reduce the need for the specific behavior.

Other trainings that may be provided, as indicated, include:

- Introduction to disability
- Philosophy of the organization regarding human rights, personal dignity, family interactions, participation in community life, and treatment in nonaversive techniques
- Individual rights
- Achieving community integration
- Positive training and support
- Confidentiality
- Conflict resolution

- Prevention/reporting of neglect and abuse
- Functional skills training
- Applied nonviolence training
- Sign language
- First aid training
- Safety practices of the work site/private company/transportation
- Social and recreational training, building a bridge between the person served and the community
- Transportation

- Utilization of community resources to meet individual needs.
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- Educational information for the employer about the individual, such as understanding about communication mode, environmental requirements, and processing patterns.
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Survey Preparation Questions

17. Does your organization provide employment services to persons served?

Yes No

If yes, identify how you incorporate the following into your services:

- Outreach to collaborate with educational resources to enhance education curriculums that address employment or future educational goals upon leaving school.

- Social skills training to enhance success in employment settings.

Life Planning

18. Based on the preferences and needs of the person served, life planning services include:

- a. Direct guidance or participation to the extent desired by the person served.
- b. Outreach/facilitation to encourage the active participation of the person served.
- c. Coordination of, or assistance with, crisis intervention and stabilization services as appropriate.
- d. Assisting the person served to achieve goals for independence as defined by the person.
- e. Optimizing resources and opportunities through community linkages and enhanced social support networks.
- f. Exploring living options reflective of the individual desires of the person.
- g. Exploring employment, career changes, or educational activities, as desired by the person.
- h. Planning for anticipated transitions as soon as the person enters services.

Intent Statements

Planning for a person and family with ASD is life long. The organization examines the individual life needs and updates services to shapes services and community resources accordingly.

Examples

18.e. Some organizations are assisting persons and families served to set up individual communities of supports for the person served as cooperatives. Considerations include:

- Revenues and expenses
- Financial trends
- Financial opportunities
- Specifying the functions and responsibilities of each party in the cooperative
- Management information
- Fiscal oversight and financial solvency, including remediation plans when appropriate

A benefits planning service can educate persons served and their families about long-term earnings, long-range budgeting, tools, and resources for ongoing benefits management.

18.g. Some persons may choose volunteerism over employment, and life planning would also apply to this.

18.h. Preferred practices indicate that if transition-from-school planning begins at least by age fourteen, the likelihood of successful transition is enhanced. In general, transition planning may be better beginning at an even earlier point based on individual needs. Families must also be included in the planning process for transitions as it can be as difficult for the family to transition their young adult into adult services as it is for the individual. This planning is further beneficial at an earlier age because the waiting list for some services may be quite long.

Survey Preparation Questions

18. Describe how your life planning services, based on the preference and needs of the person served, include:

- Direct guidance or participation to the extent desired by the person.

- Outreach/facilitation to encourage the active participation of the person served.

- Coordination of, or assistance with, crisis intervention and stabilization services as appropriate.

- Assisting the person served to achieve goals for independence as defined by the person.

- Optimizing resources and opportunities through community linkages and enhanced social support networks.

- Exploring living options reflective of the individual desires of the person.

- Exploring employment, career changes, or educational activities, as desired by the person.

- Planning for anticipated transitions as soon as the person enters services.

19. The life plan:

- a. Is individualized and person-centered.
- b. Includes long-term planning considerations in:
 - (1) Support for caregivers, including those who may themselves have special needs related to aging.
 - (2) Medical and other healthcare issues.
 - (3) Financial and estate planning.
 - (4) Family supports, including sibling supports if applicable.
 - (5) Living arrangements, including social, recreational, and community involvement.
 - (6) Career or educational development.
 - (7) Referral to resources for assistance in resolution of family conflicts.
 - (8) Implementing the life plan.

Intent Statements

The persons served or their designated advocate/guardian lead the development of the plan to the extent they desire and are able.

Examples

Specific areas of consideration may include the following:

- Education

Learning and development is a life-long process. Higher education, community college, vocational education, and individualized training should be part of a life plan.

- Estate planning

Wills and trusts and estate planning should also be considered to protect the parent and the child. Appropriate estate planning may be one that provides persons served with access to assets, while simultaneously protecting Supplemental Security Income (SSI) and Medicaid eligibility. Life insurance is an essential part of a complete financial plan and ensures protection in case of the loss of a parent.

- Guardianship

This is another issue that may affect lifelong planning and its impact on the decision-making process.

- Housing

Real estate rental or purchase, choice of group home, living with family, and residential staff supports.

- Employment

Independent, competitive employment; supported community employment; sheltered workshops; natural supports; day activities; etc., and all issues affecting life planning. Impairment-related work expenses and targeted tax credits are incentives for employment for both the individual served and the employer.

■ **Medical coverage**

Medicaid, Medicare, and private insurance are critical life-planning concerns.

■ **Recreation**

This is an area that contributes to the health, well-being, and quality of life for each individual. Television, gym access, hobbies, travel, the arts, etc., all contribute to a healthy life plan.

■ **Spiritual development**

Developing a way of living and working that brings inner peace, humility, gratitude, joy, and maturity while enhancing the life process and social interactions can be an essential part of the life plan.

■ **Earnings from employment, financial planning, SSI, and Social Security Disability Insurance**

These income opportunities are designed to fulfill basic livelihood and sustenance needs.

Survey Preparation Questions

- 19.** What is your process to ensure that the life plan is individualized and person-centered?

Does the life plan include long-term planning considerations in:

- **Support for caregivers, including those who may themselves have special needs related to aging?**
- Yes No
- **Medical and other healthcare issues?**
- Yes No

■ **Financial and estate planning?**

Yes No

■ **Family supports, including sibling supports if applicable?**

Yes No

■ **Living arrangements, including social, recreational, and community involvement?**

Yes No

■ **Career or educational development?**

Yes No

■ **Referral to resources for assistance in resolution of family conflicts?**

Yes No

■ **Implementing the life plan?**

Yes No

20. The life planning process considers daily living activities including, as applicable:

- a. **Communication.**
- b. **Budgeting.**
- c. **Meal planning.**
- d. **Personal care.**
- e. **Housekeeping and home maintenance.**
- f. **Financial services.**
- g. **Medical and dental needs.**
- h. **Community resources.**
- i. **Social skills.**
- j. **Recreational skills.**
- k. **Employment skills.**
- l. **Educational opportunities.**
- m. **Use of community transportation.**
- n. **Spiritual or religious interests.**
- o. **Safety skills.**

Intent Statements

In recognition of continuous changes in the life of persons served and families, the organization fully and comprehensively explores changes and choices in daily living.

As part of the organization's risk management, any health or safety risks identified during the planning process are addressed.

Although the persons served are always involved, because the disability is one of deficits in both socialization and communication and many cannot express themselves and do not understand complex or abstract concepts, the inclusion of advocates and/or family is also important.

Examples

20.o. Providers are encouraged to offer safety-and-risk life skills education early and often, suited to the person's ability and learning styles. For some persons with ASD, learning how to disclose is a key to their personal safety during a high risk situation, such as a sudden interaction with law enforcement professionals. Without disclosure, accommodation would be difficult to get.

Anticipating disruptive behaviors that might occur in the community can facilitate ensuring prior training for staff members, an adequate staff to client ratio, and advance planning for an emergency situation.

A web site offering some suggestions specific to the population with ASD is www.autismriskmanagement.com.

Survey Preparation Questions

20. Does your life planning process consider, as applicable, the following daily living activities:

- Communication?

Yes No

- Budgeting?

Yes No

- Meal planning?

Yes No

- Personal care?

Yes No

- Housekeeping and home maintenance?

Yes No

- Financial services?

Yes No

- Medical and dental needs?

Yes No

- Community resources?

Yes No

- Social skills?

Yes No

- Recreational skills?

Yes No

- Employment skills?

Yes No

- Educational opportunities?

Yes No

- Use of community transportation?

Yes No

- Spiritual or religious interests?

Yes No

- Safety skills?

Yes No

NOTE: The program surveyor will want to see some examples of different life plans.

21. Individual benefits planning for a person served is:
- Reviewed on a regular basis to stay current with:
 - Changes in regulations.
 - Changes in the person's life.
 - Updated so that changes that may impact the individual are addressed promptly.

Survey Preparation Questions

21. Describe your process to ensure that individual benefits planning for a person served is:
- Reviewed on a regular basis to stay current with:
 - Changes in regulations.

 - Changes in the person's life.
-
-
-
- Updated so that changes that may impact the individual are addressed promptly.
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-
-
22. At the time of development of or modification to a life plan, determinations are made for eligibility for funding sources, entitlements, and benefits.

Intent Statements

Transition planning includes community agencies, school personnel, service providers, and knowledge of potential funding sources. To be informed, make choices, and be involved, the persons and/or families served should be able to get accurate information about the organization's potential to deliver services relevant to their needs and desires.

Examples

Considerations for eligibility of the individual and family may include:

- Diagnosis (autism, Pervasive Developmental Disorder, Asperger's syndrome, IQ, etc.)
- State agencies and services provided
- Individual transition plan (residential, vocational considerations)
- Documentation (birth certificate, Social Security card, medical diagnoses, allergies, medications, and psychological/behavioral evaluations)
- Transportation

Survey Preparation Questions

22. At the time of development of or modification to a life plan, are determinations made for eligibility for funding sources, entitlements, and benefits?

Yes No

If yes, who is responsible for determining a person's eligibility for funding sources, entitlements, and benefits?

23. Life planning:**a. Is updated and adjusted :****(1) As the life of the person served changes.****(2) At least every two years.****b. Considers:****(1) Concerns.****(2) Resources.****(3) Priorities.****(4) Expectations.****(5) Beneficial activities.****(6) Alternatives.****■ Beneficial activities?** Yes No**■ Alternatives?** Yes No**Intent Statements**

Options and choices are provided for the creation of individually tailored services.

Survey Preparation Questions

23. What is your process to ensure that the life plan is updated and adjusted as the life of the person served changes?

Is life planning updated and adjusted at least every two years?

 Yes No

Does your life planning process consider:

■ Concerns? Yes No**■ Resources?** Yes No**■ Priorities?** Yes No**■ Expectations?** Yes No

