Mid West Children's Disability Services

School Age Model of Service

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WHOM do School – Age Teams serve?

School - Age Teams support children and young people who have a disability or developmental delay, and their families, who require the complexity of services and support available from a School Age Team.

Children and young people, whatever the nature of their disability, are seen at primary care level when their needs can be met there. Children and young people are supported by a School - Age Team when they have more complex needs which cannot be met within the framework of a primary care service.

School - Age Teams provide supports for children and young people who have commenced formal schooling, until they finish school (irrespective of age) or until their eighteenth birthday where they are no longer in formal education.

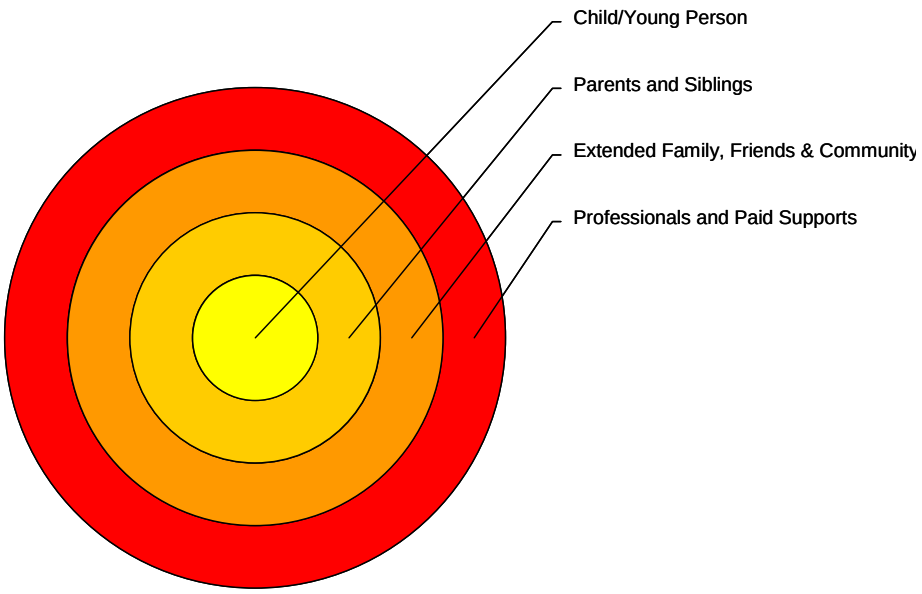
Each School - Age Team delivers supports to children and their families based on the child's school address.

WHY do School – Age Teams exist?

School - Age Teams exist to support children/young people and families to attain the best possible outcomes, for example, increased independence, participation and social relationships in family, school and community life.

School - Age Teams work in partnership with families, schools, communities and other service providers to support children and young people to achieve their full potential, to minimise the impact of disability and maximise opportunities for growth and development.

School - Age Teams are part of the circle of support around the child or young person and the focus of our work is providing the people who surround the child in everyday life with the knowledge and tools to support the child to achieve his/her potential (see diagram below). The rationale for this approach is that children and young people learn, grow and develop in the environments and with the people where they spend the most time, for example in their families, their schools and communities. It is in these everyday environments that functional outcomes are meaningful and focus on a child/young person's participation in different activities, his/her independence and ability to form social relationships and interactions with others (McWilliam, 2007).



WHAT supports do School – Age Teams provide?

School – Age Teams are made up of health professionals who work together with families, school staff and others to develop and implement evidence based strategies that will help each child and young person to reach his/her potential.

We do this through a cycle of

- Assessment of the child, young person and family's needs
- Assisting young people, families and schools in identifying their desired outcomes and goals
- Assisting in the development of strategies to be implemented at home and in school which will help to achieve the identified goals and desired outcomes
- Supporting families and school staff to implement the strategies
- Reviewing with young people, families' and schools the needs, goals and strategies to reflect changing needs.

In this way the child or young person is not reliant on intense one to one input from "specialists" but rather the people who surround the child in everyday life are empowered to maximise opportunities for growth and development in the everyday environments where they spend most time. Evidence has shown that this approach is effective in producing better outcomes for children and young people (Moore 2011). The role of therapists has shifted from the practitioner as the expert to the practitioner who shares their knowledge, expertise and experience with parents and key caregivers, through adult – to – adult relationships in which all concerned are supported in their day to day responsibilities of caring for the child (Hanft, 2004).

Teams operate an appointment based service offering planned, coordinated assessment and intervention. While not a crisis response or on-call emergency service, teams do endeavour to respond to families who may need additional support due to exceptional circumstances for a particular period of time.

HOW do School – Age Teams provide supports?

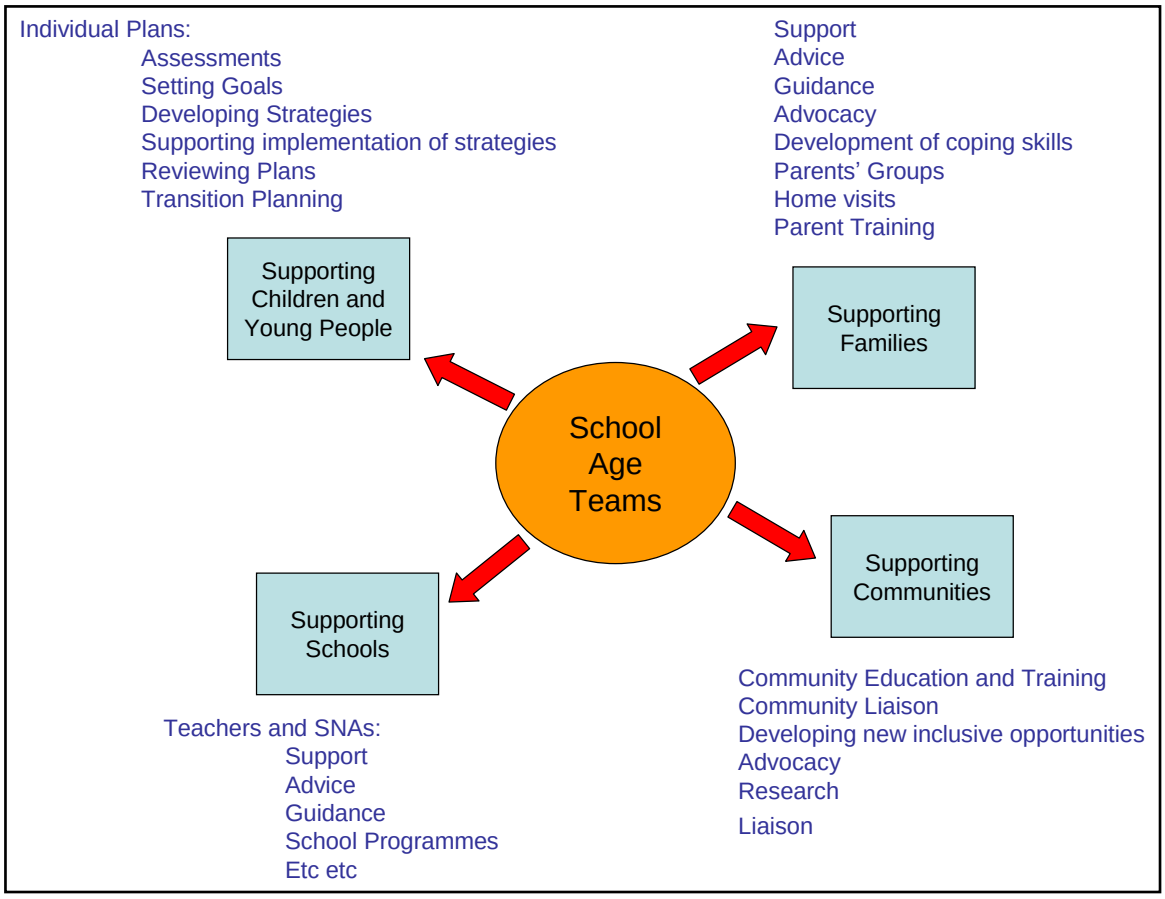
School - Age Teams in the Mid-West strive to deliver a service which is:

- Child and Family Centred (see Appendix A)
- Person Centred (see Appendix B)
- Team Based
- Outcomes Based (see Appendix D)
- High Quality
- Accessible
- Integrated and
- Safe

School – age Teams need to be aware of the importance of both Family – Centred AND Person – Centred practices given that they work with children, adolescents and young people. In particular the international literature highlights the critical importance of participation in family, school and community at all stages of the child's, adolescent's and young person's life.(see Appendix C).

Assessment and intervention is specific to the needs of the child or young person and family, emphasising capacity-building, strengthening existing skills and promoting the acquisition of new skills and empowering families to access natural and community supports, in order to achieve best possible outcomes.

The traditional clinic approach (in which children were 'treated' by specialists in clinical settings) limits the opportunities the child/young person has to practice the skills they need and cannot guarantee that he/she will transfer those skills to everyday settings (where they are needed) (Moore, 2011). Research has shown that when a parent uses a strategy with their own child it is three times more effective than when a professional uses the same strategy with the same child. The more people in the child's circle of support who have the skills needed to implement strategies to support the child, the more impact strategies will have in producing positive outcomes.(Dunst 2007). The same logic is likely to apply when appropriate strategies are incorporated into and implemented into existing school curricula, in particular to support children and young peoples' participation, independence, social competence, communication and relationship – building in school environments.



All of the above are interventions that support the child and the people involved in the child's life and are an important part of the child's individual plan.

When planning interventions the teams take into account the optimal use of resources to have the maximum impact on the maximum number of children.

WHEN do School – Age Teams provide supports?

Teams use an outcomes based approach to target their input at key stages of the child / young person's life, with reference to particular life stages, for example key periods of transition.

WHERE do School – Age Teams provide supports?

Teams provide support for children at home, in schools, at team centres and in community settings.

Appendix A

1. Family – centred practice – a definition

- A set of values, skills, behaviour and knowledge that recognises the centrality of families in the lives of children and young people

- Is grounded in respect for the uniqueness of every child, young person and family

- Is founded on a commitment to partnership with families and communities, working together as complementary equals, to support children and young people to grow, learn, engage with and participate in family, school and community life

- Puts family life – and the strengths, needs and choices of people – at the centre of service planning, development, implementation and evaluation

- Centrality of ''family life'' is crucial. It is the child, young person and family *and* everything that makes up their world their relationships, resources and daily lives; their culture, community and language; their stresses, needs, tensions and coping strategies; their preferences, interests and priorities; and their hopes, aspirations and goals

(Victorian Dept. of Human Services, Australia, 2012)

2. Family – centred practice has three elements

(i) Practices that build relationships

- Based on professionals values, behaviours and skills that help towards building positive relationships with children, young people and families

- Indicators of family – centred relational practice could include 'staff really listen to my concerns and requests'; 'staff see me and my family in a positive, healthy way'; 'staff recognise the good things I do as a parent'

(ii) Practices that support choice and participation in a partnership process

- Research literature suggests this is the most effective element of family – centred practice for improving outcomes for children and young people (Dunst et al, 2002)

- Indicators of family – centred participatory practice could be 'staff support me when I make a decision'; staff support me in making informed choices about identifying my concerns, needs and goals'; 'services provide me with options to meet my needs'; staff are flexible when my family situation changes'

(iii) Technical quality of services

- Families rely on professionals to have the knowledge and skills required to deliver high quality services and supports

- Within family – centred practice, technical quality is about professionals applying their knowledge and skills in ways that impact positively on children, young people and families

- Professionals and services need to see the knowledge, skills and behaviours required for good family – centred practice as critical areas of expertise in themselves

- The knowledge, expertise and experience of professionals complements the knowledge, expertise and experience of parents (and school personnel) and is used through adult – to – adult relationships.

(Dunst & Trivette, 2002; Moore 2005).

Appendix B

(i) Supporting adolescents/young people and their families by combining Family – Centred and Person – Centred practices

In the work of School – Age services there is an intersection of the need for family – centred AND person – centred practice. Person – centred practice is more appropriate for adolescents and young people. Person – centred practice also supports the need for School – Age Teams to review how best to think about, plan and deliver appropriate supports to adolescents and young persons (14-18 years)

The international literature places very strong emphasis on the issue of participation as a key outcome and functional skill for adolescents and young people within their families, schools and communities

- As children grow to adolescence and young adulthood, services working with them need to combine both family – centred and person – centred approaches.

- This means both respecting and responding to family members' views, concerns and knowledge of the young person, identifying and addressing their fears about the young person's future AND also respecting and responding to the young person's identified aspirations and choices and supporting the relationships that are important to his/her long – term wellbeing.

- Services need to strive to negotiate a balance based on the identified priorities (the process used to work out what things are more important than others) of both families AND adolescents/young people, being responsive to the particular stage of the young person's development.

- This is a challenging task for School – Age services as many parents work hard to enable their child's growing independence and decision – making capacity, while other parents may be less keen to prioritise their child's input into decision – making, perhaps due to family or cultural values, or because they are not optimistic about their child gaining the necessary skills, or if their views differ significantly from their child's.

- It is important for both families and professionals to keep in mind that in a world where adults often make the key decision, it can be difficult for any child or young person to have their choices heard and respected consistently. The young person may be the least likely to be vocal but the most likely to be affected by the decisions that are made. Both families and professionals invariably need to make a lot of effort to not to ignore and to pay attention to the person who ultimately has got the most at stake.

- Ultimately where family – centred AND person – centred approaches come into understandable tension, what happens will depend on many factors, including the young person's age and capacity, the decision in question and it's impacts on everybody concerned, the underlying beliefs and assumptions at play, and the professionals role and relationship with all concerned

(Sanderson, 2004; Victorian Dept. of Human Services, Australia, 2012)

(ii) Person – centred planning (PCP) with adolescents/young people and families

PCP approaches ask questions about several aspects of the adolescent's/young person's life at home, in school and in their community. Discussion with a young person and their family tends to open up the young person's world with reference to what is working and not working from their perspective, their family and school

- **Relationships** - that are important in young person's life; relationships that could be developed or strengthened; barriers to

- **Young person's gifts** - what young person enjoys, is good at, can contribute to; things person may want to do more often; the kind of people the person gets on well with; barriers to

- **Skills and interests** – what the young person enjoys or has a passion for; their talents and the things they are good at; what person can contribute; places, people and activities that help make the person happy, calm, content etc.; barriers to

- **Hopes and dreams** – finding out the direction the young person would like their life to go in; bringing committed people together around a common purpose; getting a sense of what the young person tick/what motivates him or her; barriers to

- **How to provide good support** – what exactly does good support look like for the person? Describing in detail hat people supporting the person must do; what support someone may need to participate in community opportunities, work, education; looking at ways the person might be supported to become more independent; barriers to

- **Communication** – exploring different peoples perceptions about how the person communicates; explaining exactly how the person communicates and what it means depending on context, needs, emotions etc; barriers to

- **Person's story** – landmark events in the person's life; themes that are personally important to the person; experiences that must not be repeated; celebrate achievements; identify opportunities and

positive experiences that can be built on; people or activities from the past that have gone missing and that the person might want to reintroduce

- **Health** – person's health support needs; any particular vulnerabilities that people supporting the person should be aware of; barriers to

- **How the person spends their day/week** – activities the person is already involved in; understanding more about the person's preferences so they can be expanded upon; barriers to

Types of questions that may be useful in planning

Young Person	Family
What do we like and admire about the person?	What do we like and admire about each other?
What is important to the person?	What is important to us as a family? What is important to us individually?
What is important for the person (the support the person wants or needs)	What is important for us (what support do we need as a family?)
Questions	Questions
What is working/not working from different perspectives?	What is working/not working from different perspectives?
Actions	Action

(Sanderson, 2004)

Appendix C

Participation of young people in daily life – home, school and community

- Not enough emphasis is being placed on providing children/young people with opportunities to attend accessible activities and participate in society as full community members (Leitch 2007). For example, participation in recreation and leisure activities is central to well – being and a key outcome for quality of life(Cardol et al. 2002; Dijkers 2010).

- Children and young people (with disabilities) are at risk for lower community participation (Milner & Kelly 2009) and social isolation (Shikako – Thomas et al. 2008). Young people (with disabilities) take part in fewer organised activities and are more likely to engage in passive, solitary activities such as watching television (Poulsen et al. 2007). They do not experience the widening social world of other young people (King et al. 2010) and their lack of engagement in leisure roles can affect their self – esteem, self – concept and sense of belonging (King et al. 2005; Stewart et al. 2006).

- There is an increasing understanding of the importance of ensuring that children and young people have adequate opportunities to participate in all aspects of their world, in school, leisure and recreation, and home, social and community life (King et al. 2001; WHO, 2000).

- Participation in activities is the *context* in which children and young people develop competencies, gain understanding of their strengths and abilities, form relationships and friendships, and make a contribution to their worlds (King et al. 2001)

- Through engagement and participation in different social contexts, children and young people gather knowledge and skills needed to interact, play, work, and live with other people (Law 2002).

- Children, adolescents and young adults face many obstacles and restrictions in the life experiences and opportunities needed for the development of strong self – concepts, resilient attitudes, and competencies. They typically have difficulty in attaining their goals due to prejudice, lack of skills and preparation, lack of legislation supporting inclusion and economic realities.

- Children and young people with a physical disability experience particular participation restrictions and have decreased opportunities for building relationships and often feel socially isolated (Frostad & Pijl 2007).

- They may lack the emotional support and practical assistance from peers, family members, and members of the community, such as teachers, that they require to meet their goals in life. Their opportunities are restricted by existing stereotypes, particularly the widespread belief that persons with disabilities have cognitive limitations and do not have needed skills and abilities.

- Barriers include parents' unmet needs for information, guidance, understanding and support (King et al. 2002).

- Quality of life is a useful and important outcome for School – Age Teams to consider when thinking about provision of appropriate supports to adolescents and young persons. Quality of life frameworks often focus on defining life outcomes in terms of meaningful goals, activities, and relationships ((Raphael et al. 1996).

- According to the Life Needs Model King et al. 2002) services should address

(a) foundational skills in terms of mobility, physical strength, functional communication etc

(b) activity limitations by focusing on meaningful functional skills in day – to – day environments at home, at school, and in the community

(c) interpersonal factors (family needs) and reduce participation restrictions by encouraging positive and welcoming community attitudes and policies that facilitate inclusion.

The three spheres of life constitute three intervention levels. Acknowledging the importance of the three spheres of life moves service provision to a model that looks beyond the direct needs of the child, to consider the needs of those who have important influences on the child's development.

Young Person's Participation in Reviews and Planning

- Involving adolescents and young people in decision – making processes takes time, involves developing new skills for adults and young people and can entail major shifts in attitude in services.

- Among the barriers identified are the complexity and bureaucratic nature of organisations, lack of resources, a prevalent view of children and young people (with disabilities) as being incompetent, a lack of training and support for adult facilitators and young people, and a lack of research evidence to support participatory activities (Cavet & Sloper 2004).

- The majority of young people are not involved in decision – making around their transition experiences. The small number who tend to be involved continue to be the easiest to reach, most able to communicate, the most articulate and confident (Beresford 2004).

- Participation in planning and decision – making is a continuum and the levels at which children and young people can participate includes being informed, expressing a view, influencing the decision – making process and being the main decider (Alderson & Montgomery 1996).

- For some children and young people participation may be at a level of choosing between two different options. For others this might be a starting point from which to build.

- Implications for services and families if children and young peoples' participation in decision – making is to be meaningful and effective include

    (i) Consider how to make decision – making and participation an integral part of adult's relationships with children and young people

    (ii) Consider how service inductions should contain references which highlight the importance of decision – making and participation

    (iii) Consider the need for and importance of training and staff development (Cavet & Sloper 2004; Kirby & Bryson 2002; Lightfoot & Sloper 2003).

    (iv) Consider the need for children, young people and families to have training and support if decision – making and participation is to be meaningful and successful (Kirby et al 2003)

(v) Consider and adapt to the reality that children and young people communicate in mediums other than speech

(vi) Consider in planning to ensure that processes are being put in place for children's and young people's views to be fed into decision – making that they are kept aware of what is happening and of the reasons why certain things may not be happening

(vii) Consider that much could be learned from the literature on supporting adults in decision – making. To date this body of knowledge has remained separate from that of children's and young people's decision – making and participation (Edge 2001; Ware 2004).

Appendix D

Outcomes – based approaches

- One of the most striking developments in planning and funding of human services has been the shift of focus from input/output – based models to outcomes – based models.

- Inputs are the resources that are put into the work carried out by services e.g. staffing levels, finance, time, buildings. Outputs are services delivered as part of the work e.g. amount of service provided, sometimes expressed in terms of the number of service delivery units (health statistics)

- Outcomes are defined as benefits for children, young people and families that happen as a result of service activity with them.

- Neither inputs nor outputs alone necessarily achieve desired outcomes. For example a service may have an adequate staffing level but the staff may not successfully engage parents in identifying their main concerns and the outcomes they would like for their child or young person.

- A further problem with the input/output model is that it encourages service providers and families to focus almost exclusively on the service/s to be provided e.g. speech and language therapy, rather than focus on the ultimate aim and benefits of that service for a child, thereby confusing means with ends.

- Outcomes – based models state that services cannot expect to achieve positive outcomes if they are not clear about what outcomes they are trying to achieve. Therefore to be effective it is essential there is agreement about what the desired outcomes are. Desired outcomes are generally realised through setting agreed goals and strategies to implement the goals.

- Outcomes – based models define accountability in terms of what people concerned are trying to achieve as benefits e.g. for children, young people and families.

- Thus an outcome in the context of Children's Disability Services can be defined as neither the receipt of services nor satisfaction with services, but rather what happens as a result of services provided to children, young people and families.

- Services typically find changing to an outcomes model difficult because of the prevailing service model of inputs and outputs, a tendency to confuse means with ends and the fact that professionals have frequently been trained to provide inputs e.g. speech and language therapy, occupational therapy etc. in clinic

settings without reference to context of children's experiences of daily living.

- In attempting to change to an outcomes model the following issues have been found to be of critical importance

(i) The existence of a *service culture* needs to be kept clearly in mind. The input/output and medical model is built on certain assumptions about what is important to ask questions about and measure.

(ii) In attempting to change to an outcomes model there can be a lack of appreciation of the need for *training and support.* The understanding of measurement may continue to be that it is a unit of service activity rather than an outcome or benefit for a child, young person or a family resulting from service activity.

(iii) The need to *involve staff early in the process* so as to facilitate away from the mindset that a outcomes approach is essentially about getting them to do more work when in fact it is about facilitating a mindset that asks questions about hoped – for benefits arising from their work. The latter is about having evidence as to what services are achieving by way of outcomes and benefits.

(iv) The need for *senior – level buy – in* with an understanding of the change in culture, change of mindset and change in expectations involved for all stakeholders.

(v) The need to appreciate that '*accountability'* as a concept has already been experienced in multiple ways by services staff, not always positive.

(vi) The need to appreciate that working *towards agreed outcomes is the essence of accountability,* that such work can be evaluated in terms of what is working and not working, and that accountability is not a by – word for blame and reactivity.

- An outcomes – based approach typically involves starting with the end in mind by having conversations that are helpful in identifying the outcomes/benefits to be achieved and in a sense working backwards from there, via

(i) Identify *main concerns* in order of priority (what are things to do with their child or young person that the family is most worried about? And which of these are most important to them and why?)

(ii) Identify the *desired outcomes* related to the concerns (these answer the question 'what is it you want most for your child and family, and why?') This has the advantage of focusing on what a family wants for a child or young person before they get into the question of what is to be delivered.

(iii) Translate *outcomes into specific goals* (goals are the specific targets to be met for an outcome to be achieved and answer the questions 'to make progress towards the expected outcomes what do you want or need to achieve?'; 'what specific and concrete steps need to be taken to achieve the outcome'? Goals should be measurable, realistic and achievable and worded as 'to increase' or 'to decrease' or 'to establish'. Terms such as 'strengthen' and 'enhance' should be avoided because they are vague and very difficult to measure.

(iv) Select *strategies for achieving the goals* (strategies describe how the goals will be achieved/what will be done, where, by whom, when) Strategies and activities chosen should be logically related to the desired outcomes and should be evidence – based as much as possible (known to be effective for…).

(v) Translate *strategies into specific activities* (in the outcomes approach activities are the last element to be identified while in the traditional input/output approach activities are often the first thing identified). In this step an action plan is agreed that specifies activities etc.

(vi) Identify *indicators to measure progress made* (an indicator is a quantitative or qualitative variable that allows people to verify benefits or changes as a result of intervention; they answer the question 'how do we know we are making progress on this outcome?'

(vii) *Monitoring and evaluation* of delivery and impact of activities (whether the activities happened as intended and were implemented as intended; whether the intervention had the impact as expected on the child , young person or family).