

Lakeland Centre for

F A S D

Fetal Alcohol Spectrum Disorder

Creating Touchstones Support to Adults with Fetal Alcohol Spectrum Disorder



Report Prepared by:

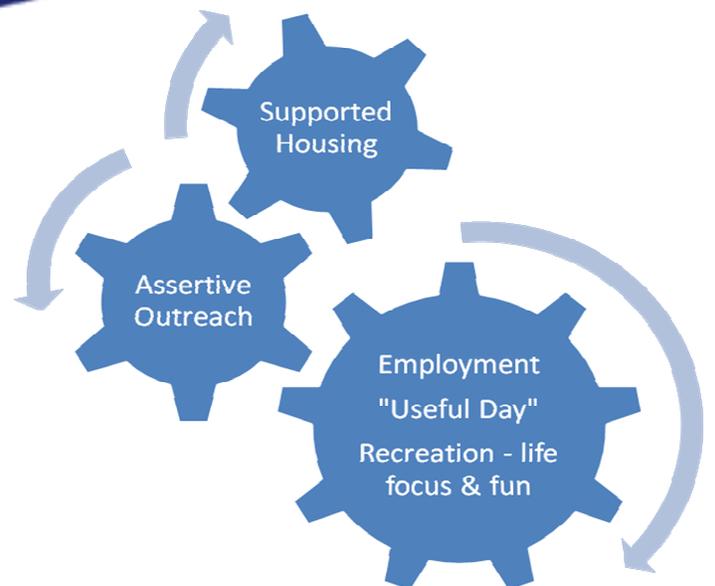
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An Alberta FASD Service Network

Touchstones

An excellent quality or example that is used to test the excellence or genuineness of others: *"the qualities of courage and vision that are the touchstones of leadership" Henry A. Kissinger.*

Touchstone - a basis for comparison; a reference point against which other things can be evaluated; "the schools comply with federal standards"; "they set the measure for all subsequent work"

benchmark - a standard by which something can be measured or judged; "his painting sets the benchmark of quality"

yardstick - a measure or standard used for comparison; "on what kind of yardstick is he basing his judgment?"

system of measurement, metric - a system of related measures that facilitates the quantification of some particular characteristic

graduated table, ordered series, scale, scale of measurement - an ordered reference standard; "judging on a scale of 1 to 10"

standard of measurement, gauge - accepted or approved instance or example of a quantity or quality against which others are judged or measured or compared

baseline - an imaginary line or standard by which things are measured or compared; "the established a baseline for the budget"

norm - a standard or model or pattern regarded as typical; "the current middle-class norm of two children per family"

By extension, the metaphorical use of touchstone means any physical or intellectual measure by which the validity of a concept can be tested (see also Acid Test, Litmus Test, Shibboleth).

CREATING TOUCHSTONES
SUPPORT TO ADULTS WITH
Fetal Alcohol Spectrum Disorders

The Context of the Report

This writer worked throughout early 2009 to gather information and a range of feedback from individuals who work closely with and for adults with Fetal Alcohol Spectrum Disorder. Approximately 24 hours of interviews took place over 9 weeks. The focus of the report is to assist in the development of recommendations for the Northeast Persons with Developmental Disabilities to overcome or minimize barriers in accessing service for difficult to serve clients – many of whom have prenatal alcohol-related disabilities.

In Alberta, there are 14 diagnostic centers that have seen a number of individuals with over 70% of those being referred being ultimately diagnosed with an alcohol related disability. The average age of individuals being seen is early childhood and many will reach the age of majority in 2020. As individuals and families already receiving services under a children's services mandate move to adult services, the expected increase in referrals will be significant. Generally speaking, 40,888 children were born in Alberta in 2004 and with the prevalence data predicting that 1 in 100 births may be developmentally impacted by substance use in pregnancy, we can expect that number to influence service delivery as well.

"We need good diagnostic interpretation – a transfer of knowledge to the community." - Social Worker

“The system has taken on FASD without much understanding so they are making some terrible mistakes” -

Trends

- More individuals with a suspected alcohol-related disability are accessing a growing service sector available for diagnostics.
- Increased professional training in FASD has increased the number of adults who fit the developmental profile of FASD to be screened and considered for diagnosis.
- More service sectors are recognizing that traditional services are not effective (and may in fact do harm) so there is pressure to support a shift in thinking outside of what currently exists
- Although they are disabled, many individuals with FASD never receive services through the system that supports Adults with Disabilities. In a paradoxical way, an individual with FASD may be treated like everyone else, which may be the worst thing for them.
- Society usually imposes the same rules, norms, and behavioural expectations on individuals with FASD as they do with all other members of society. Then, when individuals with this disability do not conform they are labelled as unusual and their problems are addressed with no apparent acknowledgement of disability.
- Most adults who are prenatally affected by alcohol are the failures of our traditional helping systems – justice, addiction treatment, mental health etc.
- There is often an overestimation of the person with FASD’s capacity to function according to societal norms.
- There continues to be “stigma” regarding the diagnosis of an alcohol-related disability.

“Your job is to interpret them to the world” –
Social Worker

Most Important Issues Facing Adults with FASD

1. Being understood as having a brain versus behaviour disorder
2. Having access to diagnostic services which includes assessment of function.
3. Access to Supportive Housing
4. Access to Assertive Outreach. Assertive outreach can best be described as a service that “goes to them” and often not predicated on the core value of “motivation to change”.
5. Having access to a “useful day” – employment, day programs, recreation and social connections
6. A focus on prevention of specialized care – mental health, addiction services and justice
7. Service to decrease the incidence and severity of secondary disabilities – homelessness, joblessness, admissions to in-patient mental health programs, interface with the justice system and having children that you may or may not be able to care for. Consideration to sexual activity, reproduction and parenting for adults with FASD is an important issue.

“As a caregiver I am always worried that whatever is being organized will not last. You are always waiting for the other

“There is a predictable deterioration of functioning when their lives go unsupported” – Social Worker

Essential Services for Individuals with FASD

Addressing the top unmet needs:

- ❑ Emergency Shelter – they often “wear out” their caregivers and are often oppositional to accepting support so consequently they have unstable housing
- ❑ Mental Health Supports – they present with many co-morbid conditions including depression, anxiety, and oppositional defiant disorder, conduct disorders that have not been diagnosed or adequately managed.
- ❑ Permanent Supportive Housing – creating placement stability is the foundation of improved case management for individuals affected by prenatal alcohol exposure
- ❑ Transitional Housing – offering flexible options that can “fill in the gaps”
- ❑ Alcohol and Drug Abuse Treatment specifically tailored to their disability and needs
- ❑ Case Management Services – providing for a coordinated response.
- ❑ Financial Management Services
- ❑ Life Skill and Employment Skills Development – training and coaching

“A lot of the support worker models are voluntary and choice driven which does not work for individuals with FASD. Where does that leave us?” – PDD client services coordinator

Housing

It is understood that a significant number of adults with FASD are likely homeless or counting on the charity of others to provide them with temporary and often substandard housing. In a study done by Alberta Health Services between August 2007 and September 2008, 1,795 homeless people were treated in Edmonton's emergency departments between them they accounted for a total of

4,348 hospital visits. The "top ten" most frequent visitors made a total of 292 trips. The number one reason homeless patients were seen in hospital was related to schizophrenia – the second was for "mental or behavioural disorders". The recommendations that came from this report – that clearly spelled out that the expensive nature of homeless extend much further than a "roof". The report also discusses the work of New York psychologist Sam Tsemberis who is an

advocate for the principles of "housing first". Tsemberis' work suggests that chronically homeless people (who often include individuals with FASD) were more likely to stay off the streets, stay off substances and to stay on supportive medications if they had housing. This report also recommended that the justice system, the child welfare system and the health care system stop releasing people without adequate discharge planning.

Challenges for Providing Services to Adults with FASD:

- They don't think they need help
- They won't ask for it

Programs that serve the needs of homeless individuals with FASD need to consider:

- Duration of service delivery
- Intensity of services

"We can actually expand their potential by creating dependency" - Advocate

"They seem to only get service when they completely fall apart" – PDD client services

- ❑ Focus of service – What are the service goals?
- ❑ Resource responsibility
- ❑ Availability
- ❑ Location of Services

Employment

People who have FASD are at high risk for having problems with acquiring and maintaining employment and for being unable to live independently* when they become adults.

**Independence* is the ability to do things on one's own without getting into trouble. This means not only the ability to perform a task, but also knowing when to do it and being willing to do it. Behavior problems can interfere with independence and often require special supervision or restrictions of some kind, as well as additional assistance with behaving more appropriately.

Employment should be:

1. **Arranged** – “found for them” since they often cannot meet traditional “job search” expectations.
2. **Supported** – i.e. getting them to work and keeping them there.
3. **Sustained** – employment can often be derailed with a ‘promotion’ to doing work that is beyond their capacity and functional skills.

“We need to get out of their way with the things they can do – praise them – but help them do what they cannot without making a fuss. Why do all service agencies want

Justice

Managing the complicated issues that surround FASD and the justice system creates situations that are often not easily fixed. It is understood that individuals

with this disability may have behavioural outcomes that place them at increased risk to interface with the justice system. More commonly it is understood that individuals with this disability are not only more likely to get into trouble but also more likely to get caught. Because they are “caught”, they are more likely to be followed and therefore more likely to stay in trouble due to non-compliance with the traditional fallout of the system. It is a vicious cycle of poor outcomes and it is these poor outcomes that can sabotage more stable options within the communities.

FASD and Addictions Treatment

Individuals with FASD are at increased risk of using alcohol and drugs and chronic substance abuse or misuse is one of the major secondary disabilities associated with having this disability.

There are several primary hurdles to successful treatment of FASD clients:

- ❑ recognition and diagnosis of FASD do not occur with enough frequency within the system of addiction treatment- professional training is largely unavailable and not a condition of employment in the system.
- ❑ the philosophic approaches that traditional treatment espouses (e.g. Insight counselling, group work) are unhelpful
- ❑ precipitate discharge and inadequate post treatment supports leave these clients floundering
- ❑ belief that client's are able to follow through at discharge – “handing their behavior back to them to manage”
- ❑ inconsistent attendance for treatment is typical of a person with FASD. This is often interpreted as being unready for addiction treatment.
- ❑ Persons with FASD often present as manipulative, unmotivated, depressed, thought disordered, in denial, or dishonest and thus viewed as poor candidates for treatment and support
- ❑ group therapy and dredging up past may cause enormous trauma and be overwhelming for these persons
- ❑ addressing their practical needs and the almost insurmountable problems of living is far more beneficial than insight work for these clients

“Our goal is to keep them safe and healthy and not posing a risk to themselves or others. Other things are a bonus...”

- ❑ their dysfunction is generally due to organicity and not alcoholism although substance use further reduces their functioning, and requires coaching to ameliorate it's effects
- ❑ worthlessness, depression, suicidal thoughts and panic are not unusual for a young person with FASD, and are further exacerbated by substance use and abuse
- ❑ the client may state strong desire to change and become self-sufficient yet this goal is frequently not realistic without support
- ❑ affected individuals who have learning disabilities and/or low IQ are at risk to be turned down for treatment
- ❑ relapse prevention should focus on increased supervision and community supports rather than increased self-monitoring by client

Mental Health Services

It is widely understood that individuals with FASD have been both over and under diagnosed with co-morbid conditions. Their behaviour(s) are generally seen as evidence of various mental health conditions. An issue that complicates matters is that each co-morbid (or co-existing) condition that accompanies an alcohol-related disability often comes with medication. It is widely understood that medications self-administered by individuals with FASD are often unsafe due to their over compliance (take too many pills prescribed by too many doctors and they are unable to be good medical historians), their polypharmacy. Their inability to report poor or ineffectual benefits or more alarmingly, unreported drug reactions.

“Mental health programming is more expensive than supporting”
– FASD parent

Ensuring that Community-Based Agencies Can Provide Services

As the population of individuals with FASD is more recognized, the demand for services will expand. Throughout the consultation process many individuals told this writer that not-for-profit agencies provide a vital role in providing services for individuals with FASD. It was heard that the challenges are in the rising demands for service and the need to recruit, train and retain a competent workforce. It was suggested that a focus be on:

1. Supporting their needs for training
2. Supporting their needs for case directed clinical supervision – difficult clients put an untold burden on day to day caregiving
3. Look at competency based system of rewards for individuals working for and with community based service delivery systems.

“Good service is predicated on available training to PDD” – client service

Families and Communities – roles and responsibilities.

It has been understood for a very long time that a significant issue that separates individuals with FASD from other people with developmental disabilities is their apparent lack of “family support”. Perhaps as many as 80% of individuals with FASD experience placement disruptions including separation from their family of origin at some point in

their life (Streissguth). For these individuals, fitting into a system that relies heavily on family support/inclusion is challenging and they often do not have the advocacy required to see them through the system’s intake processes and into service delivery. In speaking with parents who have adult “children” with developmental disabilities (that was their term in most conversations) they recognize that having their adults compliant to service delivery was almost always not an issue.

“Where would most of us be without family advocacy? We need to consider the intergenerational issues of FASD” – Parent

The families were also able to talk about the fact that their adults always received service as children and therefore saw the adult system as an “extension” of previous supports. What often happens for adults with FASD is that they have had limited if not non-existent service delivery due to having their developmental disabilities not be understood. They therefore transition to adulthood without the prior relationship to service – or their relationship with ‘service’ was not seen as helpful by them.

“When it works – it really works. We have some marvellous champions that should be recognized for their work and passion”
- Parent

Case Management Considerations

- What would it take to create placement stability for individuals with FASD?
- What do caregivers need?
- What are the most prevalent behaviors that sabotage placement
- What is success? Usually a continuum rather than a single point of measure.
- What is support?
- Systemic Failures? How will this influence their “motivation” or “willingness to engage”?
- Dependency as a useful concept – helping too much vs. helping too little

“Small systems do better work! More flexible with the rules and more responsive to relationships” – PDD client services worker

Persons with Developmental Disabilities – The Current System of Support

Developmental disability is defined by the PDD Program as a state of functioning that began in childhood and is characterized by significant limitations in both intellectual capacity and adaptive skills. The following three criteria are used to make the determination of developmental disability for PDD Program purposes:

- Significant limitation in intellectual capacity;
- Onset prior to age 18; and
- Significant limitation in adaptive skills in two or more of the following adaptive skills area;
 - communication
 - home living
 - community use
 - health and leisure
 - leisure
 - self-care
 - social skills
 - self-direction

When evaluating adults with FASD it would appear that their eligibility for services under the PDD mandate will often be in the category “significant limitations in adaptive skills in two or more areas”. In fact, most adults with FASD have limitations in all areas of adaptive functioning listed and in many or most areas of executive functioning. The difference between intellectual capacity and executive functioning deficits is largely misunderstood by the very system that is charged with the support. For the purposes of this report, this writer asked all individuals who were responsible for the care of adults with FASD in any capacity what their understanding of “executive functioning deficits” were and with the exception of two individuals the understanding was inadequate.

PDD is a family driven system that is “voluntary”. This voluntary system is largely understood to be loaded with “coercion”. Coercion is a word laden with negativity – understood to be analogous with words like force, intimidation, and oppression and

bullying. However, families living with adults with disabilities other than FASD acknowledge that their adult children are ‘coerced’ into accepting and receiving services through strong family influence. Throughout collecting information for this report it was difficult to identify how these two concepts

“If your family of origin is “broken” then there is not much advocacy. Government is not a great family substitute” – Educational Professional

(voluntary and coercion) were understood and how they were differentiated.

The process of applying for PDD services is overwhelming for individuals with organic brain disorders. The process identifies a paper application, a person to person application (interview) and the required documentation supports that are necessary to initiate an application for service. Below I will try and identify what the barriers are for persons with FASD attempting to access the system.

1. Because of their deficits in executive function, individuals with FASD are the least likely of any group to consider themselves disabled and the least likely to see that they need help.
2. One participant reported that the first question that got asked of the adult that she was supporting through the PDD application process was “do you have a disability”? Not surprisingly the candidate replied “no”. The interview was over very quickly. It should be noted that perhaps this was an issue of professional competency because other examples given did not give this context but this issue should still be considered.
3. Their unstable living arrangements and lack of advocacy often means that documents gathered in their childhood that would clarify the need for support in adulthood are often missing, lost or never gathered.
4. Individuals with FASD have an “invisible” disability – they always sound more competent than they are. To make matters worse, they work very hard to have individuals think they are capable so often hide their histories of not functioning and have a very rosy picture of their future without supports.

“Support can be normalized with early diagnosis.”
PDD Client
Services Worker

“It is much less expensive to prevent problems than to deal with the fallout.” –
Adult Service
Agency

5. There are significant challenges around dealing with informed consent. For the purposes of this report, “informed consent” is described this way:

Informed consent is a legal condition whereby a person can be said to have given consent based upon a clear appreciation and understanding of the facts, implications and future consequences of an action. In order to give informed consent, the individual concerned must have adequate reasoning faculties and be in possession of all relevant facts at the time consent is given. Impairments to reasoning and judgement often make it impossible for someone to give informed consent.

6. There are further challenges with what is considered a “restrictive procedure” within the framework for practice and the mandate of PDD. The general description of restrictive procedures is: “Day to day care giving practices that limit, restrict, or control aspects of behaviour that any other adult would have the right to choose for themselves.” Acknowledging the brain based behaviours which often accompany FASD means that some supports necessary to assist an individual with FASD may be considered “restrictive” and not willingly administered by programming ultimately resulting in poor outcomes for the individual. Direct examples could be (but are not limited to) managing their time, money, relationships and hygiene.

“Sometimes I see that they are ‘independent’ but they have zero quality of life. Is that what we call working?” – PDD

If an individual is ineligible for PDD services, intake coordinators provide referrals and information on other programs and services that may be more appropriate. If questions arise concerning eligibility, intake coordinators ask for professionally documented information that identifies the individual's disability. This is often not available.

WHERE DOES THIS LEAVE US?

Traditional systems of support – like PDD – are designed to offer service that is “palatable” to the general public watching (policies of empowerment, self directed case planning, independence, self

“We must take the issues surrounding FASD on! We are naive to believe they go away.” – Social Worker

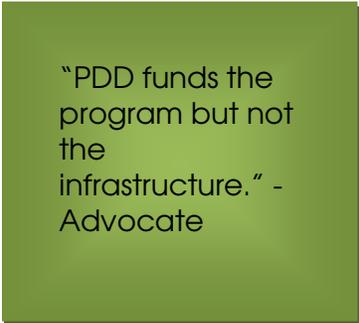
management and self regulation etc) and these are often not compatible for individuals with this disability. It is, however, acknowledged that this growing population is currently and will continue to be in need of service. We know that service – directed to key areas of need – will minimize the need for service long time. We know that service will decrease both the incidence and severity of secondary disabilities. We know that adequate and appropriate service will support the complicated issues that surround the intergenerational issues of FASD. We know that service will ‘anticipate’ crisis and avoid costly and more challenging outcomes. The cost of “non-involvement” is well documented and there is no need to replay that here for the purposes of this report.

Lakeland Center for FASD is offering the community one of the few opportunities to have adults with this disability diagnosed and understood. For that reason, this region could become a best practice example of how to deliver appropriate FASD interventions. I am suggesting that there are two options:

1. Support a shift in thinking within the current system of PDD supports. To accomplish this would require an allocation of funds to support staffing, funding and training. There are approximately 9,100 Albertans receiving support under the PDD umbrella. The average cost per case is \$60,000.00. Accepting adults with FASD would significantly raise the numbers being served under this mandate. From all consultation, however, the feedback has been that the costs per case would be significantly lower than the ‘average cost per case’. Most working in the field believe that mentorship to support the areas of functioning that are often requiring support would cost approximately \$6,000.00 per year. That number came from the costs commonly associated with “mentorship” roles in service delivery. (First Steps and Step by Step programming).
2. The other option – that has received great support through consultation and this report – is to enhance the AISH Benefit Program to include both financial management as well as “services’ specific to the deficits in adaptive skills and executive function. The AISH Benefit Program is described on the government website:

What is the AISH Benefits Administration Program?

This is a program to help you take care of the money you get from AISH. Your participation in this program is voluntary. If you decide to participate in the program, your AISH cheque will be sent directly to the [Office of the Public Trustee](#). You make the decisions about how your money will be spent. You will get help setting up a budgeting plan from someone you know (called your Primary Contact Person) and the Office of the Public Trustee will follow your plan. If, at any time, you want to change your budgeting plan, you and your Primary Contact Person will make a new Instruction Form/Budget and send it to the Office of the Public Trustee. They will then follow your new plan.



“PDD funds the program but not the infrastructure.” - Advocate

The benefits of this applying this program to the service needs of adults with FASD versus the traditional PDD program may not be well articulated as yet, however the community service sectors describe it as working exceptionally well for individuals with FASD. This may be explained in part by the way a plan is presented to the participant and system’s awareness that once a plan is put in place (with little to no fan fare) the individual with FASD is likely not going to agitate to the plan. Thus, the same issues that prevent them from getting things started are the ones that keep them moving along once things are put into place

In summary:

The transition to adulthood is a journey that all are required to make. This paper was organized to explore the complexities of doing this transition when you have developmental needs that are largely misunderstood. In trying to find a system that is willing and able to do this complicated work it came to the point that there is nothing currently available that could do this without issue. The PDD system is the most currently suggested and referred to but all involved suggest that the paradigm shifts required to have this done easily will create a heavy systemic toll. The AISH Benefits Program that is working nicely for a sub-set of individuals with this disability has limits to its service abilities and must have “added values” for it to work.

Recommendations:

1. Individuals with FASD start adult life earlier and with few supports. As a consequence they have expensive and catastrophic outcomes in their lives – poverty, social isolations, justice related consequences, addictions that are unrelenting and usually not easily supported etc. In order for PDD to support this type of developmental trajectory, they need to work collaboratively with systems that clients they are serving are interfacing with. This can be accomplished through a “case plan review” process where the partners come together to consult on best practice options for the adult with FASD. Case Plan Review increases the circle of influence, provides “training” and advocacy and expands skills and knowledge beyond the case managers capacity. Case Plan Review also understands the concept of “collective wisdom” and can support the “trends” of resource issues/needs. **The recommendation to PDD is to create opportunities for case plan review.**
2. Investing in the development of consensus designed to assess the functional capacities and limitations of individuals requesting supports will yield improved outcomes all by themselves. Who applies for disabilities supports when they

don't need them? Most applications to PDD for individuals with FASD are initiated through systems of disability supports in the children's service delivery system (Child Protection, FSCD (Family Support for Children with Disabilities)). The question arises when that system evaluates service need one way and the adult system begins the process all over again. **In recommendation, could the PDD system manage eligibility through consensus?**

3. Using social mapping to illustrate the lack of "family supports" will promote the need for more formal community supports. This could be part of the application process. As PDD was historically a "family driven" system it was likely developed without this issue in mind. **The recommendation to PDD would be to add 'social mapping' to their application process as a further determinant of need.**
4. It has been widely understood that if you "manage" the money of individuals with FASD, the majority of their issues are managed. For that reason, this report has illustrated that in looking at what is working there was opinion that the AISH Benefits Program was a system of support for individuals with FASD. **The recommendation to PDD would be to engage further with this program.**
5. Informing public policy on supports for adults with FASD is, without a natural advocate, failing. Those doing this currently look like they are 'self serving' and are often discounted. **The recommendation to PDD would be to engage the community partners in both the assessment of eligibility phase as well as the determination of service need.**

We must tell the story! We must link both positive and negative outcomes to the availability and unavailability of appropriate service delivery. What makes things work? What happens when it doesn't? Through the preparation of this paper, it was very clear that there are many people doing wonderful things for an often very difficult client population. In most cases these dedicated individuals were "working off script" and doing many of the things outlined in the recommendations. To

support this thinking, and looking at one thing that could improve both the process and the outcomes, would be to consider case plan review as a mandatory occurrence in service.

Case Plan Review Framework for Practice

1. Reporting to the Case Review Committee is simply a meeting of the team responsible for the care of the individual. This team consists of all key players and invited “specialists”.
2. The draft case plan is presented with a clear picture of the assessment and the agreed upon plans designed to minimize risk and enhance permanency planning.
3. Case Plan Review increases the circle of influence, provides “training” and advocacy and expands skills and knowledge beyond the case manager’s capacity.
4. Case Plan Review understands the concept of “collective wisdom” and can support the “trends” of resource issues/needs.

In finalizing the plan we hope to:

1. Ensure that the plan is based on current research and effective practice.
2. Include a variety of approaches in intervention that are geared to the specific needs of the individual/caregivers.
3. Base all recommendations on a comprehensive assessment.
4. Guarantee that the case plans are supported by a multidisciplinary team that includes caregivers
5. Ensure that it is reflective of the individual’s needs.
6. Provide outcome-based information to our funders and community and government partners.
7. Support the concepts of “cross training” and shared “work”.